Candidate Education Booklet

Solid Organ Transplant

INTERLINK®
COE NETWORKS & PROGRAMS

Promoting
Medical Excellence

Candidate Education Booklet
SOLID ORGAN TRANSPLANT

Dear potential transplant candidate:

INTERLINK created this booklet to share information about the transplant process and to help guide you in selecting a transplant program. This includes:

- ***Basic information about organ transplant***
- ***Frequently asked questions***
- ***List of helpful organizations and links***

We encourage you to discuss this information with your physician, transplant team, and case manager. As you gain more understanding of the transplant process, we hope this guide will help you ask the right questions, encourage you to seek additional information, understand the way organ transplant programs vary and ultimately select the right center for you. If you have already selected your center, this booklet will help to highlight the choices and many new experiences you will have in the weeks and months ahead.

As we emphasize throughout this guide, the ultimate decision is yours to make. Your doctor, your case manager, physicians, and staff at proposed transplant centers can provide the expert guidance you may need to make this very important decision.
We wish you the best on your journey to health.

Disclaimer:

As you and your physician review this information, understand that this booklet and the information contained within is provided for informational purposes only. It is not meant to imply that a transplant is medically necessary, is medically appropriate for your condition, is a covered benefit or meets your plan criteria. Those decisions are rendered solely by your health benefits program sponsor.

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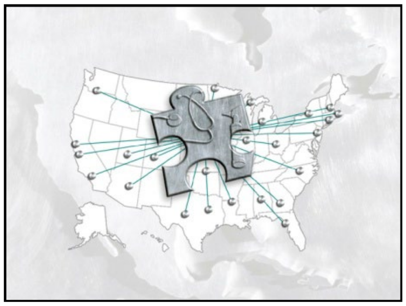
Seeking Transplants on a National Basis

***Seeking Transplants** from the Highest Performing Programs in the Country*

The National Organ Transplant System

In 1984, the National Organ Transplant Act (NOTA) established the federal government's role in overseeing the organ transplant system in the US. The legislation created the Organ Procurement and Transplant Network (OPTN) and the Scientific Registry of Transplant Recipients (SRTR). It also created a framework for organizations dedicated to the procurement of organs for transplantation (OPOs). The OPTN creates policies that govern the allocation of organs across the centers, the quality standards for transplant programs and OPOs and what information needs to be collected to monitor performance and compliance. OPOs identify deceased donors and offer organs to waiting candidates according to prevailing OPTN policy. The SRTR uses the data collected by the OPTN to analyze results and simulate new policies. The SRTR also creates program specific reports for every program in the country, summarizing each program's performance individually and relative to other programs. These reports are publicly available at SRTR.org



Transplant Programs

There are transplant centers and programs across the US although they are not evenly distributed. Using a sophisticated performance model, INTERLINK has developed a national network of the highest quality programs. This is called a Centers of Excellence (COE network). Only a few companies like INTERLINK offer access to exclusive COE networks. INTERLINK works with many of the country's insurance companies and health plans to make access to the COE as seamless as possible.

Some people choose to be cared for at transplant centers far from home because there are no transplant centers in their area. Others select distant programs because the program has top-rated performance and outcome statistics. Finally, some patients select a program because it's a benefit offered through their health plan. Choosing a transplant center may be one of the most important decisions you will make. Bear in mind that different centers will select different types of patients to place on their transplant waiting lists. Selecting a high-quality program with proven results for treating your condition should be a primary goal.

This booklet is prepared specifically for transplant candidates and their families, so we hope you find this information helpful. We use the most current research and statistics to produce this booklet. INTERLINK'S transplant experts reviewed it completely for accuracy.

Many centers specialize in specific conditions so it is possible that INTERLINK or your physician might recommend going to a center farther from home to get this specialized care. If you or your physician would like more in-depth information about a transplant center in INTERLINK's COE network that we have highlighted in the supplemental information included with this booklet, ask your case manager or contact the medical center transplant coordinator directly.

Checking Your Benefits

You should be sure to understand your health insurance benefits thoroughly before accessing transplant care. Most health plans have pre-certification programs, and once notified that you are being referred for evaluation, the plan will likely choose to monitor your care from that point on.

Many insurance companies and health plans use case managers to help coordinate care for people with complex medical needs. If so, your case manager will prove to be a valuable resource as you seek care and utilize your benefits.

Seeking Additional Information

We encourage you and your physician to review the information contained herein when planning your treatment program. It is likely that as you move through the process you will acquire new information that will raise additional questions. Locating a person who is qualified to answer your questions is often difficult. Here are some suggested places to search for answers:

- Your health plan sponsor
- Your case manager
- The transplant coordinators at the center or centers you are considering
- The Resource Guide in the back of this booklet
- United Network for Organ Sharing (UNOS) – 1-888-894-6361, www.unos.org
- Our website at www.interlinkhealth.com

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Frequently Asked Questions

Frequently Asked Questions

Evaluating Transplant Programs

How do I go about evaluating and comparing program statistics?

Evaluating and selecting a transplant center is a decision best made between you and your physician. As mentioned above, current program outcome statistics for every transplant program in the country are listed at http://www.srtr.org. These statistics are updated in January and July each year. Annual transplant volume information for each center can be found at www.optn.transplant.hrsa.gov/. This site is updated every few weeks. For many programs you will find valuable information on the transplant program's web site. You can find links to all programs in the INTERLINK Transplant Network on the INTERLINK COE Networks & Programs web site at https://interlinkhealth.com/transplant-and-specialty-networks/.

Is there a single statistical indicator that would indicate the "best" program?

No. You will get excellent services and results at any qualified transplant center. Using a "Centers of Excellence" designated transplant center is not a guarantee of superior outcomes. Experience, as is common with most skilled professions, is often a reliable predictor of a favorable outcome. The number of years the medical center has been doing transplants, the total number of transplants performed since inception and the number of transplants performed annually are all good indicators of experience. The SRTR web site provides all this information and more for each transplant program and compares the individual metrics with regional and national benchmarks - srtr.org

Questions To Ask When Choosing a Center

What types of transplants does your center do?

Most centers specialize in certain organs. Only a few of the national centers do all types of transplants. Centers that have long experience with a high volume of transplants of the organ of interest usually have the greatest commitment to supporting that program with the most physicians and other resources. We recommend that you take advantage of the depth and breadth of experience that only the large transplant centers can offer.

How long has your (organ) program's team been together?

Experience in transplantation is important. The longer the team has been together the better. Like other complex procedures performed on very ill patients, you can expect the best outcomes from the most experienced teams. In general, you want to consider programs where the entire team including the surgeons, the medical specialists, subspecialists, nurses, coordinators, social workers, pharmacists, etc. has been working together for at least two years.

What are your outcomes?

Centers should be willing to share their experience with you. There are three internet-based resources that provide individual statistics on solid organ transplant programs: www.srtr.org, www.unos.org and http://optn.transplant.hrsa.gov/. The outcome information listed on www.srtr.org is risk-adjusted. Risk adjustment means that results are "adjusted" for the risk factors in each transplant and compared with results for patients with similar risk factors across the country to be sure these comparisons are "apples to apples." These risk-adjusted comparisons let you know how one center's results compare with what is expected at other centers taking all these factors into consideration. This is a more accurate way of comparing the outcome statistics from center to center. A complete explanation of risk adjustment is given at www.srtr.org.

What is the experience of the physicians on your staff?

The more years of experience the transplant physicians, other medical specialists and subspecialists have, the more likely they will be able to avoid complications and successfully treat complications should they arise. All transplant physicians at your center should have specialized training in transplant medicine or surgery. See American Society of Transplant Surgeons (ASTS.org) and American Society of Transplantation (AST.org) for physician training information.

What is the experience of your nurses?

Like physicians, the experience of the individual nurses and the nurses working together is an important consideration. A high functioning support and care team directly influences outcomes and program performance. There are formal training programs and certifications for transplant nurses conducted by the American Board of Transplant Professionals. Most high-quality programs will have members on their teams with these certifications

Can you put me in touch with one or more patients who have undergone the same transplant recommended for me?

Because of privacy concerns, it is understandable that some centers may be reluctant to give you the names and contact information for previous patients. But you should ask. Many programs have lists of patients who have volunteered to be available to transplant candidates to answer questions about the transplant process and about the center. Their experience can be invaluable. You can derive important insights into whether this center is the right one for you.

Do you have a support group for patients and their families?

You should expect that any center you choose will have a well-organized patient support group. Support for you and your family will be very important as you move through the transplant process. Many of your questions and concerns can best be addressed by people who have experienced what you are about to experience. Large, long-standing transplant centers have very active groups of patients, former patients and families that are eager to share their experiences with you and provide whatever help they can. Look on the center's website for information about their support group or call the transplant coordinator at the center and ask for more information.

What is your visitation policy?

Most transplant centers have generous visitation policies for critically ill patients. However, immediately after your transplant, your immune system will be suppressed to help your body accept the new organ. Consequently, doctors may want to limit your interaction with outsiders to reduce the risk of getting an infection during this period. Each center will have its own policies for handling this period and the risks associated with it. Ask the transplant coordinator how they regulate the flow of visitors.

Do you allow rooming-in?

Many centers will allow rooming-in to a certain extent and/or provide some type of accommodation in the hospital itself, thus enabling families to be close to the patient during critical times. Because of the increased risks for infection immediately after the transplant, the center may not allow rooming-in during that period. Ask the transplant coordinator.

Insurance and Other Financial Questions

What are my in-network and out of network benefits?

Most health plans have at least two levels of transplant benefits: in-network and out-of-network. In-network benefits provide you with the most dollar coverage but may restrict your access to certain doctors and hospitals. If you have out-of-network benefits, you will have greater freedom in choosing your doctor and hospital, but you may be required to pay more “out of pocket” for your services with these providers.

Check with your insurance carrier to determine if the transplant center to which you were referred, or that you have chosen, is in-network or out-of-network. This could have important financial consequences for you. In general, it is a good idea to be evaluated at an in–network center for transplant care. The INTERLINK Transplant Network chooses its participating centers with great care. Only the highest performing centers have been invited to participate in this network. Other centers may or may not have the experience or comprehensive facilities that are available through INTERLINK centers. You need to understand your benefits fully and the advantages one center may offer over another before you decide. Ultimately, the decision is yours.

Is there a limit on how much my health plan will pay for my transplant?

We advise you to contact your plan to understand your transplant benefit and the type of plan in which you are enrolled, to determine your coverage and its interpretation of “essential health benefits.” A successful transplant is not only good for the recipient; it accrues fewer charges paid by the insurance plan.

What is the lifetime maximum benefit? Do I have this limit in my health plan? If so, how much is it and how much, if any, have I already used up?

Insurance reform has mandated that lifetime maximum limits on the dollar value of “essential health benefits” may not be established. This means that, if your plan has defined transplant care as an essential health benefit, there cannot be a maximum limit set on how much the insurance company will pay for this care. Although lifetime maximum limits are gone, we advise you to contact your plan to understand your transplant benefit and what related care is interpreted as an “essential health benefit,” and what your potential out of pocket costs are likely to be.

Does my insurance cover the full cost of organ donation?

You must check with your plan. Not all health plans cover all or even part of the cost of organ donation.

Organs can be obtained from deceased donors or from living donors. If your plan covers the cost of organ donation it generally will cover the costs associated with the recovery and processing of an organ from a deceased donor. Health plans may be more restrictive when it comes to covering the cost of an organ from a living donor. Some may cover the cost only if the donor and recipient are enrolled in the same health plan. Others may cover the cost of the living donation procedure, but not subsequent complications associated with donation if they occur. Even for living organ donors with good health insurance coverage there generally will be out of pocket expenses such as travel, accommodation, or lost wages from missed time from work.

If my insurance does not cover all the cost, where can I get financial assistance?

The first place to turn to is the transplant center you have chosen. Speak with the financial coordinator. The financial coordinators in large national centers have had years of experience working with people to solve the most challenging financial questions. This experience is yet another example of the depth and breadth of experience of the transplant team you will find in large national transplant centers that may be lacking in smaller programs.

Living donors can get financial support in some cases from the National Living Donor Assistance Program at https://www.livingdonorassistance.org/.

Note: Also, check the Financial Assistance section in the Resource Guide at the end of this booklet. Several organizations are listed that may be able to provide direct support or advice.

Coordination of Benefits (COB)

In addition to your health plan, there may be additional insurance coverage available to you. These resources include Medicare and Medicaid. There are programs for specific illnesses (Medicare coverage for certain patients with end stage renal disease or ESRD, for example) or for individuals with disabilities (Medicare coverage under certain circumstances for patients with chronic disabilities). You need to check with the financial coordinators at the center you have chosen. These professionals are very familiar with program eligibility criteria for these programs and possibly others.

Travel and travel benefits

Check with your health plan to see if there is financial assistance for travel, lodging, meals, and incidental expenses while away from home for transplant related care. Many health plans provide benefits to help with these expenses. Frequently, the benefit may only be available to you if you remain in the network and utilize an in-network participating transplant center.

Housing

Most large transplant centers can arrange temporary housing for you and your family. Many centers own apartment units that are available to transplant candidates and their families. The cost for facility owned housing ranges from nothing to a small charge that is well below what you would have to pay if you rented the same apartment or hotel room on your own. If the center does not own housing, they usually have arrangements with nearby hotels, apartments or corporate housing units for their patients and families who must remain in the area for an extended period. You should check with the transplant financial coordinator, or the transplant social worker assigned to you. Schools for children who can't be left with relatives during the pre- and post-transplant periods are available at many of the large transplant centers.

Jobs and income

You need to check with your employer, as every company has its own policy. Whether or not your job is protected may depend on whether you are the patient or the caregiver. Most employers will be very understanding of the needs of the entire family. But this is a highly individual decision, and one employer's policy may be very different from the next. Please check with your HR department for your company's policy.

Initial Evaluation

Where will it be done?

Most centers do the pre-transplant evaluation in person at the center, although more recently there are a few doing evaluations via telemedicine. Check with the center you have chosen.

How much of it can be done by my local doctor?

Most of the testing can be ordered and supervised by your own doctor. The specialists at the transplant center will work with your doctor to coordinate the testing. The results will be shared with your doctor and the specialists at the transplant center.

Will I have to be admitted to the hospital for my evaluation?

In general, all pre-transplant testing can be done as an outpatient except when your condition requires you to be hospitalized. As mentioned above, telemedicine may be an option. Occasionally, centers do require that the patient be admitted to the hospital for testing, but this is not the case at most centers. Check with the center you have chosen to learn about their policy.

How long will it take?

A new patient evaluation generally takes 1-3 days. These are typically full days. The evaluation typically involves several appointments with the physicians and coordinators who will work with you throughout the pre-transplant and post-transplant period. If specialized testing is necessary, usually it will be scheduled at the time of the initial evaluation.

Where will I stay?

The financial coordinator or social worker can help you arrange housing for the duration of your evaluation.

How soon after the evaluation will they let me know if I am going to be listed?

This varies quite a bit from one center to another and even from program to program within a center. A lot depends on how complex your case is, whether additional, specialized testing is required, how many patients they are evaluating, and several other factors that determine the work schedule at the transplant center. In general, most centers will provide a report to you and your physician within a few days following your evaluation.

Selection Criteria

Selection criteria for accepting transplant candidates?

Every center may have somewhat different selection criteria depending on their experience and the research interests of the medical team, but they all adhere to standard guidelines that have been agreed to by OPTN member institutions.

The Selection Committee

When all test results are available following your evaluation, your case will be presented to the selection committee. Usually, the selection committee is made up of the entire transplant team, including the transplant surgeons, transplant medical specialists and subspecialists, nurse coordinators, the head nurses of the inpatient transplant unit and clinics, transplant pharmacist, social workers, financial coordinators, and the program director. Patient selection is a group decision within the committee. Selection is made according to previously determined selection criteria that are based on OPTN guidelines, the latest scientific evidence, and the experience of the center.

If I am turned down by one center does this mean that I will be turned down by every center?

No. Each center may look at your case differently. If your condition does not meet standard OPTN criteria for listing, you still may be accepted by a center that specializes in taking care of patients with your condition or that has a special research interest in newer treatments for patients with your condition. A lot will depend on the experience of the medical team managing patients with your condition. It may be advisable to check with a prospective center to see if your condition meets their selection guidelines.

Can I be listed at more than one center?

Yes. There are no restrictions for a prospective transplant candidate to be evaluated and registered at more than one transplant center. However, each transplant center may have their own policies for accepting candidates already registered at another center.

Who pays for the second (or third) evaluation?

You need to check with your health plan. Your health plan may allow you to have a second evaluation at a different center if you have been turned down at the first center. Each health plan will have their own policy, and you should check with them regarding multiple evaluations/listings.

Waiting Lists/Listing and Multiple Listing

How are donor organs distributed?

Solid organs are registered and distributed through the Organ Procurement and Transplant Network (OPTN) that operates 24/7 using complex and well-established computer driven policies. Medical need is the most important factor, along with distance from the donor center, disease type, body size, blood type, donor age, tissue matching, and, to a much lesser extent, length of time on the waiting list. Patients with the most pressing medical need, along with the appropriate tissue match typically receive organs before other patients.

Are donor organs distributed by region of the country?

Donor organs are distributed based on how far the transplant center is from a donor hospital and then by severity of disease. These are complex algorithms, and you can get detailed information by going to this link: https://www.unos.org/policy/policy-brochures/.

If I am evaluated and accepted at a transplant center in a different region from where I live, am I limited to organs available at the national level?

No. Once you become a transplant candidate, and are registered on the OPTN list, you then become a candidate at the transplant center. You will have the highest priority for organs from donors in hospitals close to your hospital but still can receive offers from across the country.

When do I start accumulating waiting time?

After a transplant center has evaluated your medical condition and determined that you meet their criteria for a transplant, they will register you with the OPTN. For kidney transplant candidates, wait time is calculated from the date they started dialysis. Otherwise, new registrants start accumulating waiting days once the registration process is complete and you become listed as a candidate on the UNOS waiting list. However, keep in mind that length of time on the waiting list has less priority than other factors for most organ offers per current OPTN policies.

Do I lose waiting time if I am removed from the list?

If your transplant candidacy status is changed to "inactive" by your transplant center due to either improvement or deterioration of your medical condition, you will not lose your accumulated OPTN waiting time. You do not, however, accrue additional time until your candidacy status is changed back to "active." If your transplant candidacy status is re-activated by your transplant center, OPTN is notified and you start accumulating time again, which is added to the time accumulated before the inactive status. Some of the rules about this are quite complicated and further information about the implications for you is best discussed with the transplant center.

How does waiting time accumulation work if I am registered at more than one medical center?

While waiting time is cumulative, it is not additive. This means that if you are registered at two transplant centers, you cannot add the waiting time accumulated at those facilities together. For example: if you are registered at transplant center "A" for 45 days and registered at transplant center "B" for 10 days, this does not mean that you have earned 55 days on the transplant list.

Can I transfer my accumulated UNOS waiting time to another transplant center if I am successfully evaluated?

UNOS generally allows you to transfer your accrued waiting time to the new facility. This means if you have accumulated 45 days at transplant center "A" and you become a candidate at transplant center "B," you can usually transfer your 45 days accumulated to center "B." In this case, your waiting time at center "A" will revert back to zero. It is advisable to check with prospective medical centers about their rules in this matter before you are evaluated.

Pre-Transplant Period

Important people you'll want to get to know!

The following people will be very important in your life after you are listed for a transplant. Get to know them well. They will work closely with your doctor and your health plan's case manager. You should feel comfortable going to any of them when you have questions. When it comes to a transplant, no detail can be considered too small to mention or discuss. Your transplant team will help you organize and understand the details in your ongoing care so that you will be in the best possible condition when the time comes for you to receive your new organ.

- Your local doctor
- Your health plan case manager
- Transplant surgeon
- Transplant physician
- Transplant coordinator
- Transplant social worker
- Transplant financial coordinator
- Transplant pharmacist

Do I have to move to the city where I will get my transplant?

Possibly temporarily. It depends on the organ and the center. Ask your transplant center.

How close to the hospital do I have to be?

Check with your transplant center. As your time to receive a new organ gets closer, the center may require that you move closer to where the transplant will take place. A lot depends on your condition, the organ and how far away your home is from your center. Each center has its own policies. This is something they will cover with you during your evaluation. If you have additional questions after your initial evaluation and listing, call the pre-transplant coordinator that has been assigned to you.

Who will help me when I go to the transplant center?

Transplant coordinators will help you with housing and local transportation. Most often, transplant candidates arrange to bring with them a "caregiver" through the transplant admission and following stay. A caregiver is typically a family member or close friend. Caregivers play an important role but do not need any special medical training before they arrive.

Will anyone help me with the expense of going to and from the center and the cost of lodging when I am there?

Check with your health plan. Some plans have transportation and lodging benefits that will help to pay for some and possibly all the expenses associated with traveling to the transplant center. Others do not. You need to ask your health plan's case manager.

Can my caregiver get time off from work?

This is highly variable from employer to employer. Check with your HR department or the HR department where your caregiver works. Being a caregiver is an important role, but often an uncompensated one. The Family Medical Leave policy may be a good option depending on how this is administered by the caregiver's employer. https://www.dol.gov/agencies/whd/fmla

Do I need to have any special dental work done before the transplant?

Check with the transplant center. You should ask about this at the time of your initial evaluation. The transplant physicians may want you to have all dental work completed before your transplant. It is good to ask so that you can have it done if they feel it is necessary.

What is my local doctor's role?

The transplant center will keep your local doctor completely informed about your medical status and progress through the transplant process. Before your transplant, you will probably receive most of your care from your own physicians working closely with the doctors at the transplant center. For the first several months following the transplant, most of your care will be managed by the doctors at the transplant center. The duration of frequent visits back to the transplant center after your transplant depends a lot on your condition and if there are any unusual treatments that are required. Most transplant centers want you to return to your local doctor for most of your care at some point after your transplant and will work with your local doctor when it is medically appropriate.

Of course, there will always be a need to return to the transplant center occasionally according to their treatment protocols and your condition. They will work closely with your doctor to try to keep these trips to a minimum. The transplant team will send your doctor regular updates after your visits and will involve your doctor in telephone conferences as necessary to ensure that he/she is kept up to date.

Transplant Period

How am I notified that an organ is available?

The transplant center will call you. As the time draws close for your new organ, you may be given a beeper or pager so that you will always be able to receive a call.

How do I get to the hospital?

If you live far from the transplant center, the center will probably have already worked out the travel arrangements for you. When you are nearing the top of the list, your center will assess the travel time to the center. If this time is too long, you will probably be asked to relocate to be close to the transplant center. If this is the case, the coordinators and social workers at the center will work with you to help you find affordable housing during that period.

How long will I stay in the hospital?

Following the transplant, the hospitalization is quite variable depending on your condition going into the transplant and the type of organ transplant you receive. In the case of kidney transplants it is not unusual for patients to go home after 5-7 days.

Can my family stay with me?

The transplant center will encourage your family and especially the person who will be your primary caregiver to stay with you throughout the entire transplant period. Many facilities will make special arrangements in the hospital so that your loved ones can be close to you during this critical time.

Post-Transplant Follow-Up and Care

Immunosuppressive medications

The body's immune system's natural response to foreign tissue, like a transplanted organ, is to attack it. This immune reaction is called transplant rejection. Contrary to the finality of the sound of the word, more than 95% of rejection episodes are reversable. Consequently, transplant rejection is more a process than a final event. Immunosuppressive medication is used to prevent or reduce the severity of the rejection process. While almost all transplant recipients will need to take antirejection/immunosuppressive medication for the rest of their life, research over the last 20 years has dramatically reduced the complications and side effects of these medications. Every transplant program uses a similar but slightly different protocol for immunosuppression after an organ transplant. The vast majority of these regimens use much higher doses early after the transplant and lower the doses over the first few months after the surgery.

Who pays for my medicine?

A complete list of commonly used immunosuppressive medications can be found at www.transplantliving.org. You will find the typical indications, dosages, side-effects, food interactions, and commonly asked questions about these medications at this website.

Other medicines

All post-transplant protocols include infection prevention medications. Viral and fungal infections that are rare in immune-intact people are much more common after transplant. For this reason, solid organ recipients are prescribed antiviral and antifungal medication after transplants. These preventive medications are also covered by most insurance plans.

How long do I have to stay close to my transplant center?

After the transplant, each center has different policies. In general, you will need to be within easy travel distance to the center for about a month after discharge. If you are doing very well and you have easy access to transportation from your home to the center, you might be able to return to your home sooner. Usually, in the first few weeks after your discharge, the transplant team will want to see you up to 2-3 times a week. After that, the period between clinic visits will gradually increase and the frequency can be managed more easily from a distance.

How often do I have to come back?

Ask the transplant team. Each program will have somewhat different schedules or protocols that they follow. Your follow-up visits will be very precisely scheduled to ensure you are seen at the right time for important blood tests and other tests to track the function of the new transplant and the status of your immune system.

What happens if I have a complication?

You will be given a special number to call in the event of complications during the immediate post-transplant period. If you think you are having a complication, you should call this number immediately and speak to or page the coordinator. Coordinators are specially trained to evaluate any changes in health after transplant and advise on what to do in every circumstance. They may advise you to return to the transplant center, go to your local hospital, get your blood drawn ahead of schedule, or plan a clinic visit. If you are referred to your local doctor or hospital, the coordinator will contact them to let them know about your condition and any special concerns that they need to address when you are seen. The transplant team will be talking with the other physicians at every step to ensure that you are being managed appropriately.

What happens if I get a fever?

Call your coordinator immediately. A fever may be nothing to be concerned about, but after your transplant you will be on immunosuppressive medicines to prevent you from rejecting your new organ. These same medicines make it more difficult for your body to fight infections. Early diagnosis and treatment of rejection episodes or infections in transplant patients is critical so be sure to contact your program right away. Let the transplant team decide if your condition is minor or needs immediate attention.

Who do I call?

Call the special number you have been given by your transplant center. This will put you in touch with the post-transplant coordinator who has been assigned to your case. These coordinators are specially trained to handle everything from the most serious emergencies to the simplest procedural questions. They are your best source of information after you have been discharged.

Medications

Who pays for my medicine?

Most health plans offer benefits for your immunosuppressive medications after you have left the hospital. Medicare will pay for the immunosuppressive medications for patients after a kidney transplant for up to three years following the transplant. Check with your health plan representative. If your health plan or Medicare does not cover the cost of the medicines, many hospitals and drug companies have programs to help you with some of the costs. Your post-transplant coordinator will be able to help you. Most programs have specialized pharmacists to help guide medication selection and provide patient information about insurance coverage.

How much does the medicine cost?

The actual cost varies quite a bit depending on the organ, your age, your general state of health, complications, and many other factors. Transplant medications and their costs vary tremendously and depend on the individual center's medication protocols, the amount and type of immunosuppressive medication used for different organ types, antiviral and antifungal preventative medications chosen and whether infections or other complications develop. Transplant centers can provide rough estimates for expected out of pocket costs depending on the type of transplant and the recipient's insurance coverage. Most health plans offer benefits that cover all or part of the cost of these medications. Check with your health plan representative to be sure. There are plans with special limitations for organ transplantation. You need to find out exactly what your plan will cover and what it will not. Ask specific questions and do not assume that you are fully covered.

Complications of the Transplant

Rejection

The body has the natural tendency to reject your new organ. It is normal. Your body and immune system are programmed to recognize foreign tissues and organisms. After an organ transplant from anyone other than an identical twin, you must take medications to prevent your immune system from reacting against the "foreign" new organ. These medications are powerful and very effective. Doctors have come a long way in understanding how to block the immune response more precisely against transplanted organs thanks to the development of new medicines. Nonetheless, many transplant patients will experience one or more episodes of rejection. These are usually mild and, if caught early, are easily treated. It is rare that a rejection episode has long term effects on organ function.

Your doctors will be testing you regularly for signs of rejection. Most often evidence for mild rejection shows up in the routine blood tests before any symptoms develop. However, some patients have fever, malaise, or pain that can be signs of rejection. It is important to identify and treat rejection episodes quickly. You must notify your doctor if you feel symptoms that you think might be attributable to rejection.

Other Problems After an Organ Transplant

As effective as the immunosuppressive medicines are, they can have side-effects associated with them. These are listed below.

- **Elevated Cholesterol**
  Elevated serum cholesterol can be a side effect of anti-rejection medications. To reduce the risk of developing elevated cholesterol, you will be given instructions on your diet and may have to take medicine, called a "statin", to lower your cholesterol. Commonly used statins include Lipitor, Pravachol, Mevacor, Crestor, Zocor and others. Your team might prescribe other cholesterol lowering drugs.

- **Diabetes**
  Diabetes can be one of the side effects of transplant medications. Diabetes after transplant is often associated with prednisone, one of the immunosuppressant medications which you will take immediately after the transplant. Most transplant programs have protocols to quickly reduce the amount of prednisone early following the transplant to limit side effects. In other cases, it may not be given at all. Rest assured that your physicians will be doing what they can to reduce the amount of this medicine. There are many research protocols underway to further reduce or eliminate the use of prednisone altogether. Inquire at your center if you are interested in participating.

  Because of the tendency to develop diabetes following a transplant, you will be given a diet to follow that will be low in sugars and saturated fats. You will need to watch what you eat carefully to prevent diabetes and prevent the build-up of cholesterol.

- **Obesity**
  Newer immunosuppression protocols, use of less prednisone, and careful attention to diet have helped to reduce the incidence of obesity after transplant. However, this is still a concern so your transplant team will encourage you to follow a healthy lifestyle and eat a balanced diet that is low in sugars and saturated fats. Physical therapists will work with you in the hospital and your team will give you a graduated exercise regimen that will also help to reduce the chance of developing diabetes or gaining excess weight. Continuing exercise after leaving the hospital is highly encouraged.

- **High Blood Pressure**
  Along with obesity, elevated cholesterol and diabetes, high blood pressure (hypertension) can occur. More recently however, newer drug combinations have reduced the chance of developing

high blood pressure after transplant. But if you had high blood pressure before your transplant you might require different or more treatment afterward.

Social Issues

Dependence on others?

This may be the hardest thing for many people to accept. You will come to rely very heavily on your caregivers and your social support system to help you get through this experience. It is important to choose the right caregiver to provide the most support, and that you and your caregiver form a team to work with your doctors and focus on all aspects of the complex transplant process. Your transplant program will work with you to identify a stable support system since this is an essential part of a successful long-term outcome.

Caregiver's needs?

Caregivers get tired too. Many caregivers experience physical and emotional challenges during the first few months after your transplant. There are many support groups available for caregivers. Some of these are included in the Resource Guide at the end of this booklet. There are other sources as well, so make use of all the resources that your transplant center coordinators and social workers have available to them to help you and your caregiver.

Sex?

Ask your doctor how soon you can resume your normal sexual activity.

Job?

The goal of the transplant is to return you to good health. This means that you should be able to go back to work at your old job. Patients who have fully recovered after transplant surgery have few restrictions placed on their activities. It is very likely that you will be able to function entirely normally. Your transplant team will advise you about the timing of returning to full physical activity and work. But, in general, you should be able to go back to your former occupation without limitation.

Other Health Issues

You will always have to remain in contact with your transplant team. Your local physician will probably resume much of your care; however, the issues surrounding organ transplantation are so complex and the medical regimen so exacting that you will always want to remain in contact with the transplant team. It is critical that you keep your return appointments to the transplant center for regular checkups even if it is only once a year for a routine exam. This lets everyone, including yourself, know that you are following your prescribed treatment plan, that you understand how to care for yourself and your new organ and that you are doing well.

Promoting
Medical Excellence

Candidate Education Booklet
SOLID ORGAN TRANSPLANT

Patient Resources

Resource Guide

What follows is a table of resources that are available to you either on the internet or by telephone. The list is not necessarily complete and INTERLINK does not specifically endorse any of the organizations whose contact information is presented. You should investigate any source of information carefully before making important decisions. Ultimately, the best source of information about your transplant will be given to you by your physician and the physician's support team at the transplant center or centers you are considering.

The single best publicly available resource for learning about solid organ transplantation has been prepared by the United Network for Organ Sharing (UNOS) and can be found at www.transplantliving.org. We strongly recommend that you refer to this resource and to the website of the transplant center or centers that you are considering. In addition, most transplant centers have their own web sites that can provide lots of information about specific contacts, general processes for evaluation and post-transplant care, local housing, and transportation information, etc. The transplant center websites frequently contain the most up to date list of housing options and other current information that will be of importance to you.

Web Links

General Information	
Scientific Registry of Transplant Recipients	srtr.org
United Network for Organ Sharing	unos.org
American Society of Transplantation	https://www.myast.org/
American Transplant Foundation	Americantransplantfoundation.org
American Organ Transplant Association	aotaonline.org
Association of Organ Procurement Organizations	http://www.aopo.org/
Donate Life America	http://donatelife.net/
Children's Organ Transplant Association (COTA)	www.cota.org/

Heart and Lung Transplant	
American Heart Association	http://www.heart.org/
American Thoracic Society	http://www.thoracic.org/
International Society for Heart and Lung Transplantation (ISHLT)	http://www.ishlt.org/
Second Wind Lung Transplant Association, Inc.	http://www.2ndwind.org/
Lung Transplant Foundation	https://lungtransplantfoundation.org/resources/
American Lung Association	lung.org

Kidney Transplant	
American Kidney Fund	http://www.kidneyfund.org/
American Association of Kidney Patients	https://www.aakp.org/
American Society of Nephrology	https://www.asn-online.org/
Forum of ESRD Networks	http://www.esrdnetworks.org/
National Kidney Foundation	https://www.kidney.org/transplantation/
National Living Donor Assistance Center	www.livingdonorassistance.org
Renal Support Network	www.rsnhope.org
National Kidney Foundation	www.kidney.org

Liver Transplant	
American Association for the Study of Liver Diseases	http://www.aasld.org
American Liver Foundation	http://www.liverfoundation.org/education
Children's Liver Association for Support Services (CLASS)	www.classkids.org/

Pancreas, Kidney/Pancreas and Islet Cell Transplant	
American Diabetes Association	http://www.diabetes.org/
Clinical Islet Transplantation Consortium	http://www.citisletstudy.org/

Financial Assistance/Information	
HelpHOPELive	https://m.helphopelive.org/
Patient Advocate Foundation	http://www.patientadvocate.org/

Drug Assistance	
Transplant Recipients International Organization (Pharmaceutical Compassionate Programs)	https://www.trioweb.org/
Needy Meds	http://www.needymeds.org/

Support Organizations	
Family Caregivers Alliance	https://www.caregiver.org/
Family Voices	http://www.familyvoices.org/
National Alliance for Caregiving	http://www.caregiving.org/
Caregiver Action Network	http://www.caregiveraction.org/
ARCH National Respite Network	http://archrespite.org/
Rosalyn Carter Institute	http://www.rci.gsw.edu/
Starlight Children’s Foundation	http://www.starlight.org/
Well Spouse Foundation	http://www.wellspouse.org/

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