

Before Your Transplant

When you decide to get a transplant, you are entering a battle of sorts—against your own immune system.* Your *immune system* is essential to your survival. It helps fight off infections and disease. But your immune system doesn't always know what's best for you. Getting a new organ(s) is a positive thing for your health. It will improve your quality of life and may add years to your life. But your immune system can see a transplanted organ as a foreign invader. Unless steps are taken to stop it, your immune system may launch an attack against the new organ and try to destroy it. This process is called *rejection*.

Many ways have been discovered over the last three decades to prevent and treat rejection. One of the most important is the *anti-rejection medicine*, which you will take after your operation. These drugs suppress, or hold back, the immune system so that it doesn't attack your organ. (See Life After Your Transplant for more details on anti-rejection medicines.)

The battle to keep your transplanted organ starts long before you are rolled in for surgery. It begins right now in the pre-transplant phase. You'll have to undergo various tests and evaluations to make sure that you are healthy enough to handle the stress of a transplant. We will also be doing some tests to find out what organ will be a good match for you. Your immune system is less likely to attack an organ that is more *compatible*

*See the Glossary for a more detailed definition of all the words that are identified in *italic*.

immune system – An important part of your body that defends you against infections and disease. The immune system also attacks anything that it thinks is foreign or strange, including a transplanted organ. Anti-rejection medicines help stop the immune system

from attacking a transplanted organ.

rejection – When the body tries to attack and destroy a transplanted organ or tissue. There are three types: *hyperacute rejection*, *acute rejection*, and *chronic rejection*.

with you. In addition, your overall health is important to the success of your transplant. A healthy body helps keep a transplanted organ healthy, too.

The pre-transplant period is a time of evaluations, tests—and waiting. This chapter provides an overview of what you can expect to go through. However, every patient's experience is somewhat different, depending on his or her medical and personal issues. If you have any questions, please talk with your pre-transplant coordinator. The pre-transplant coordinator is a registered nurse who will be handling all of your transplant care until you are admitted for your transplant surgery.

Your Transplant Evaluation

IN SHORT

First, you will need to have some tests and exams. These will tell us if you are healthy enough for a transplant.

You will also meet with the surgeon. Your pre-transplant coordinator will set up all your tests and meetings.

Your tests and exams will take about a month. Then, we will tell you if a transplant is a good option for you.

An organ transplant can be a major strain on your heart, lungs, and the rest of your body. It also can be hard on you emotionally. So, we need to make sure that you are healthy enough to handle a transplant. This is why we ask you to have a number of tests and evaluations before we take you on as a patient.

anti-rejection medicine – Drugs that weaken or suppress the *immune system* so the body will not attack and reject a transplanted organ. These drugs are also called immunosuppressive medicines. Common

anti-rejection drugs include cyclosporine, prednisone, tacrolimus, azathioprine, and mycophenolate.

compatible – When one person (the donor) can safely give an organ to another person (the recipient). Also called "a good match."

transplant cardiologist – A physician who specializes in caring for the cardiac (heart) health of transplant candidates and recipients.

echocardiogram – A painless test that gives us a detailed picture of your heart. Echocardiograms use ultrasound, or sound waves.

stress test – A test that shows us how well your heart works under stress. This test involves walking on a treadmill with monitors on your chest. Patients who are unable to exercise can lie down during a stress test and receive medicines to speed up your heart rate.

What Tests and Evaluations Can You Expect? The number and type of tests and evaluations you will need depends on your medical history. For instance, an older patient who has a history of cancer or heart problems will need to undergo more tests than a younger, healthier patient. Your pre-transplant coordinator will tell you exactly what tests and evaluations you require. This list may include the following:

- Various blood tests to assess your kidney and liver function. You will also be tested for HIV, hepatitis, and other infectious diseases. We will also find out your blood type and perform other blood tests that will later help us find you a suitable organ. (See “Finding You a Compatible Organ,” pp 8.)
- A chest x-ray to look for any lung or heart disease.
- A consultation with our *transplant cardiologist*, a heart doctor who helps care for transplant patients. This exam may include the following tests:
 - o An *echocardiogram*, a simple and painless test that uses sound waves, or ultrasound, to provide a detailed picture of your heart.
 - o A *stress test*—if you have diabetes or are over age 40. This test involves walking on a treadmill with monitors on your chest. Patients who are unable to exercise can lie down during a stress test and receive medicines to speed up your heart rate.

- o A *heart catheterization*—if you have known heart problems or have an abnormal stress test. This heart test tells us if any of the arteries that supply blood to your heart are clogged. A thin tube (or catheter) is inserted into an artery in your arm or leg and guided to the arteries of your heart.
- A dental exam to check for gum or tooth infections, which can cause problems after a transplant.
- A *cystogram*, if you are seeking a kidney transplant and have diabetes or have had bladder problems in the past. A cystogram shows the size and function of your bladder, where urine from the kidney is normally stored. The test involves placing dye into your bladder and taking an X-ray picture.
- An evaluation by our *transplant social worker*, who understands all of the emotional, social, and personal issues facing transplant patients. The social worker is interested in your emotional health and how well you will be able to handle the responsibility of a transplant. For instance, after your transplant, will you be able to take all of your medicines as prescribed? The social worker also tries to help you think of—and address—any non-medical issues that may affect the success of a transplant. For instance, how will you get to and from the hospital? Can you rely on your family or friends to help you through your transplant?

heart catheterization – This heart test tells us if any of the arteries that supply blood to your heart are clogged. A thin tube (or catheter) is inserted into an artery or vein in your arm or leg and guided to the arteries of your heart.

cystogram – A test to find out the size of your bladder and to see if it works well.

transplant social worker – The University of Chicago Hospitals social worker who helps transplant patients with practical, financial, and emotional issues.

*transplant
financial**coordinator –*

The transplant team member who helps you with insurance and financial issues.

- A consultation with our *transplant financial coordinator* who knows all the ins and outs of paying for a transplant. (See Financial and Insurance Issues chapter for more information on finances.)
- Routine health screenings. We will check to make sure all of your screenings are up-to-date. These tests are based on your age and gender and may include:
 - o A gynecological exam for women, including a Pap smear, to rule out any infections or disease
 - o A mammogram for women over the age of 40
 - o A PSA (prostate specific antigen) blood test for men over age 50 to test for prostate cancer
 - o A screening exam for colon cancer for men and women over age 50.

If any potential health problems are spotted during the transplant evaluation, additional tests or exams may be needed.

Your First Meeting with the Transplant Surgeon. At some point during the evaluation period, you will meet one on one with a *transplant surgeon* and your pre-transplant coordinator. As part of this meeting, you'll be asked various questions about your health history, and the doctor will conduct a complete physical exam.

The rest of this meeting is informational.

The transplant surgeon will discuss whether

*transplant**surgeon –*

A surgeon who performs transplant operations.

transplantation is a good treatment for you. He or she will also explain all of the various transplant options that are available to you at the University of Chicago Hospitals. Together, you will come up with a plan to optimally and safely treat your medical problems. You'll also learn more about the entire transplant process—from finding a suitable organ to the medicines that you will need to take after surgery. (See Table 1, page 31.) Be sure to ask lots of questions during this meeting. The more you know about the transplant journey, the more prepared you will be.

Where Can You Go for All These Tests and Evaluations?

We can arrange for you to receive all of your pre-transplant tests at the University of Chicago Hospitals. Or, if you prefer, you can get the standard medical tests—such as blood tests and chest x-ray—at another hospital or doctor's office. In some cases, your insurer may not cover some of these tests unless you arrange for them through your primary care doctor.

However, you will need to come here for at least some of the evaluations, including:

- Your meeting with the transplant surgeon and pre-transplant coordinator.
- Your evaluation by the transplant social worker.
- Your meeting with the transplant financial coordinator.

Talk to your pre-transplant coordinator about how you want to handle all of this. Also, be sure to tell your coordinator if you had some of the tests done recently for another medical

reason. In these cases, we can get a copy of the results so that you may not have to repeat a test.

Your pre-transplant coordinator will set up all the tests and evaluations you're having done at the University of Chicago Hospitals for you. Out-of-town patients usually only have to come to Chicago for one or two days. Your pre-transplant coordinator can help you find hotel accommodations during your visit, if needed.

When Will You Find Out if You're a Transplant Patient?

The testing period usually takes less than a month. Once your tests and evaluations are complete, the transplant surgeon and the rest of the transplant team will review the results. Together, the team decides whether a transplant would be the best treatment for you.

Then, your pre-transplant coordinator contacts you to let you know whether we've decided to take you on as a transplant patient. The vast majority of the people we evaluate are taken on as potential transplant patients. In certain cases, patients will be asked to take care of certain health issues before we will consider them for a transplant. For instance, a patient may first need to lose weight or quit smoking to help ensure that the transplant is safe and successful.

Finding You a Compatible Organ

IN SHORT

We can put you on the waiting list for an organ. These organs come from people who have died. Most people have to wait months or years for an organ.

If you need a kidney, think about finding a living donor. Any adult who is healthy can donate a kidney. Kidneys from living people do better than kidneys from people who have died.

We need to find you an organ that is a match for you. If you and the donor are not a match, your body may reject the organ. How do we tell if a donor is a match? By comparing your blood with the donor's blood.

As discussed above, your immune system will view a transplanted organ as a foreign object. In fact, only identical twins can share organs without worrying about organ rejection. The remaining majority of transplant patients need to take precautions against rejection.

Three Compatibility Tests. How do we determine compatibility? With the following three blood tests. We use the same three tests whether you are going to have a transplant from a living donor or from a deceased donor:

- Blood type. Your blood type must be compatible with the donor's blood type:
 - If your blood type is O, then the donor's blood type must be O.

HLA antigens – A blood test that helps match a recipient with a donor. Antigens are proteins found on the surface of all the cells in your body. You inherit Antigens from your parents. During this blood test, a set of the donor's Antigens

are compared to the recipient's Antigens to see how well they match. We look for a match of zero to six. A match of six is best. HLA tests are also called "tissue typing" or "genetic matching."

- If your blood type is A, then the donor's blood type must be either A or O.
- If your blood type is B, then the donor's blood type must be either B or O.
- If your blood type is AB, then the donor's blood type can be A, B, AB, or O.

In some cases, we may be able to use special blood "washing" techniques to help match a transplant patient with a living donor who has an incompatible blood type. If this is possible, we will discuss it with you during your pre-transplant workup.

- HLA, or human leukocyte antigens. *Antigens* are proteins found on the surface of all the cells in your body. There are hundreds of different types of Antigens. Some people refer to HLA antigens as "genetic markers" because you inherit these proteins from your parents. Blood relatives are more likely to share the same Antigens than non-relatives are. So, too, are people of the same race or ethnic group. During this blood test, a set of the donor's Antigens are compared to your Antigens to see how well they match. We look for a match of zero to six. A match of six out of six is best. But this only occurs one out of four times between siblings and less than 10% of the time with deceased donors. In the past, we looked for the best Antigen match, either with a living donor or a deceased donor.

That's because a donor organ with a good HLA match was less likely to experience rejection. But now that we have better drugs to prevent rejection, even an organ with a zero HLA match can work well and remain free of rejection after transplant. So, there are many more potential donor options for you.

- **Crossmatch.** During this test, a sample of your blood is mixed with a sample of the donor's blood to test for a *positive crossmatch* or *negative crossmatch*. A positive crossmatch means that you have developed antibodies, or an immune response, to something in the donor's blood or tissues. If you have a positive crossmatch, it is likely that your immune system would attack and destroy the organ(s) from that donor. Therefore, the transplant team will usually only accept organs that show a negative crossmatch with your blood.

Keeping an Eye on Your Antibody Level. Before your transplant, we will regularly test your antibody level to see how likely you are to have an immune response to a donor organ. The human body tends to produce antibodies in response to any substance it considers foreign, such as a transplanted organ. A past transplant may increase your antibody level. So can a blood transfusion. Women may also produce antibodies in response to the babies they have delivered.

positive crossmatch – Occurs when two people are **not** compatible, when this happens the recipients immune system may destroy the organs of that particular donor.

negative crossmatch – Occurs when two people are compatible, therefore, a transplant can occur.

PRA – A test to see how high your antibody level is. The more antibodies in your blood, the higher your PRA.

highly sensitized – When you have a lot of antibodies in your blood. This can occur because of a past transplant, pregnancy, or blood transfusion. Highly sensitized people have a harder time finding a suitable donor.

To tell how high your antibodies are, we use a test called a *PRA*, or panel reactive antibody. Your PRA can vary from 0 to 99%. The number relates to the percentage of the population that you would likely react against if they were to donate an organ. For instance, a PRA of 10% means that you might be incompatible with organs from 10% of the population.

Some patients are *highly sensitized* because they have lots of antibodies. These patients are more likely to react against a potential donor organ than a patient with fewer antibodies. The transplant team may consider giving highly sensitized patients medicines before their transplant in order to lower their antibody level. Other possible treatments include washing the patient's blood through a machine to remove some of the antibodies. This may be discussed with you during your evaluation.

The Living Donor Route—for Kidney Transplants. We encourage all of our kidney transplant patients to explore a living donor transplant. There are several advantages:

- You won't have to wait a long time for your transplant. Your surgery will be scheduled as soon as you and your donor finish your evaluations.
- Living kidneys are usually in better shape than deceased donor kidneys because they are removed from a healthy donor. Living kidneys can also be quickly transplanted from the donor to the recipient. As a result, living donor organs are very likely

to work right away. Your hospital stay may be shorter and your recovery may be faster after a living donor transplant than a deceased donor transplant.

- Living donor kidneys often last longer than kidneys from deceased donors. On average, a kidney from a living donor has a greater than 95% chance of working well after one year. In contrast, deceased donor kidneys have a 90% one-year survival rate. Living donor kidneys, on average, work for 15 or more years. Deceased donor kidneys function for an average of eight to 10 years.
- A living donor kidney may be the best option for patients with high antibody levels. The best-matched donor can be selected. Plus, special treatments can be given prior to transplant to lower the risk of rejection.

Living donor kidney transplants are also an option for patients who need both a kidney and a pancreas. We perform the kidney transplant first, from a living donor. Then, you are put on the waiting list for a deceased donor pancreas. Once you have recovered from your kidney transplant (usually within four to six months), you can undergo a second transplant surgery when a compatible pancreas is available.

There is one disadvantage to a living donor transplant over a deceased organ transplant: Someone whom you care about must have one of his or her kidneys removed. On average, people who donate a kidney live just as long as people with two kidneys. Most donors fully recover from the surgery in a few weeks and never develop any health problems that are

directly related to donating a kidney. If the donor is in good health before surgery, removal of a kidney does not affect his or her health.

However, even though the risks are low, becoming a living donor is a major commitment. For Living Donors: What You Can Expect chapter can help your potential donor figure out if kidney donation is something he or she wants to do.

Who Can Become a Living Donor? Anyone who is 18 years of age or older and is in good health can undergo testing to become a living donor. The donor must sincerely want to give one of his or her kidneys and must do so on a voluntary basis. Both men and women can be good kidney donors.

People with major health problems, such as high blood pressure, diabetes, cancer, or obesity, cannot donate an organ. Sometimes, the operation is too risky for these people. In other cases, their kidney might not function after transplant or they may be at risk of developing future kidney problems of their own.

Living organ donors may be a relative or a non-relative. A blood-related family member, such as a brother or a daughter, is more likely to be a good genetic match (ie, have a better Antigen match) than a non-blood relative. But all living donor transplants, including those obtained from non-relatives, tend to be very successful. In addition to blood relatives, potential living donors include a husband, wife,

in-law, or close friend. Some of our patients also find living donors through their church or a community organization.

Once a living donor is found, he or she will need to undergo a thorough medical evaluation that is similar to the one that you had done. Your pre-transplant coordinator will let you know whether your potential donor is a suitable candidate. Then, a date for transplant surgery might be set. Both you and your donor will undergo surgery on the same day.

If your living donor is not suitable, we can put you on the waiting list for a deceased donor kidney. If you like, we can continue to evaluate other potential living donors while you are on the waiting list.

The Deceased Donor Organ Route. When living donation is not an option, we put your name on a waiting list to receive an organ from a deceased donor:

- You are put on a list of patients waiting in Illinois and northwest Indiana. Gift of Hope Organ & Tissue Donor Network is the *organ procurement organization* (OPO) responsible for our local area. Whenever a potential organ donor is identified in this area, Gift of Hope is notified.
- You are also placed on a national waiting list that is maintained by the United Network for Organ Sharing (UNOS). UNOS is a non-profit organization that oversees the nation's organ transplant activities.

*organ
procurement
organization
(OPO) –*

OPOs recover and transport deceased donor kidneys and pancreases. There are 59 OPOs in the United States. All of them are part of

the United Network for Organ Sharing (UNOS). The OPO that serves most of Illinois is Gift of Hope Organ & Tissue Donor Network.

These waiting lists are actually computerized databases. They contain vital information on every potential transplant recipient in the country, including blood type and HLA type. Gift of Hope also keeps a blood sample for you on file to test your compatibility with a deceased donor organ (ie, with a crossmatch test).

Every time an organ donor becomes available, people at Gift of Hope, UNOS, and the local transplant centers rapidly begin the steps that lead to transplantation. Here's how the process unfolds:

1. A patient dies in a local hospital. Most organ donors die from a brain injury or stroke. In these cases, the patient has died, but the kidneys and other organs are still working with support from machines and medicines. The donor's family donates the organs to give others the gift of life.
2. Gift of Hope sends a procurement team to the hospital where the donor is located. This team removes the organs and collects vital information about the organ and donor, including the organ's size and condition, blood type, and HLA type.
3. Gift of Hope sends all the vital information about the organ and the donor to UNOS. UNOS checks its national database to see if a "perfect match" is available anywhere in the United States. You would qualify as a perfect match if your blood type and HLA type match as best as possible with that donor. Kidneys and pancreas' that are very well matched tend

to work the longest. So, organs are first offered to any recipient who qualifies as a best possible match. This is true even if it means the organ(s) has to be shipped from Illinois to a far away state like California. The same would be true if your best-matched organ became available out of state. The OPO where the donor was located would be asked to ship the organ to the University of Chicago Hospitals for you. Thanks to advances in organ preservation, organs can be sent long distances for transplantation.

4. If no best-matched recipient can be found, then Gift of Hope gives the organ to a patient waiting for transplant at one of the eight transplant centers in Illinois. "Perfect matches" are not that common. So, most organs that become available in our local area end up being transplanted in local recipients. To find a suitable recipient in the area, Gift of Hope runs a list of all of the potential patients at local transplant centers who have a compatible blood type with the donor. This list is ranked according to:

- How long you have been on the waiting list.
- How good your HLA antigen match is with the donor.
- Whether you have any extra "points."
Extra points are given to children, people who donated organs in the past, and patients who are difficult to match due to previous transplants or transfusions.

The organ is then offered to the first patient on that waiting list. If that patient cannot be transplanted for some reason, the next patient on the list is offered the organ.

5. A final crossmatch test between the donor and the potential recipients is performed. This final test determines which of the recipients are compatible with that donor. The organ is then sent to the transplant center with the highest-ranked compatible recipient. Please note: You will **not** lose your spot on the waiting list if you are ill when an organ becomes available or if you have a positive crossmatch with a potential donor organ. You will maintain your place and will be considered for the next potential donor organ that becomes available.

Although waiting time is the major factor in ranking on the list, it is possible to be offered an organ any time after you are placed on the list. For example, you may be offered a “perfect match” organ within weeks or months of being put on the waiting list.

The Waiting Game: Preparing for a Transplant

IN SHORT

While you are waiting for your transplant:

- **Keep yourself healthy.**
 - **Tell us about any big changes in your life.**
 - **Let us know if your insurance or doctors change.**
 - **Give blood samples every month.**
 - **Get ready for your hospital stay and recovery**
-

The wait for a transplant can be hard, especially for patients who are waiting for a deceased donor organ. Here are some tips on how to get through this period—and be ready for your new life after your transplant.

Keep Yourself as Healthy as Possible. The healthier you are before your transplant, the better your body will be able to handle the stress of surgery and post-transplant care.

Here's how to keep yourself in good health:

- If you're on dialysis, try not to miss any treatments.
- Consume a healthy diet. This can be difficult when you are on dialysis. So, seek the help of a nutritionist—either our *transplant nutritionist* or the nutritionist at your dialysis center.

– Avoid too much salt/sodium and fluid.

A high-salt intake can make you thirsty, which

*transplant
nutritionist—*

One who specializes in caring for the dietary needs of transplant candidates and recipients.

may cause you to drink too much fluid. People who frequently eat out or consume a lot of convenience or processed foods have a harder time controlling their salt and fluid intake than those who eat home-cooked meals.

- Watch your intake of potassium and phosphorus. Too much potassium can cause nausea, an irregular heartbeat, and heart attacks. Food items that can cause blood potassium levels to become high include: avocados, potatoes, and concentrated items such as juices and tomato products. Too much phosphorus over time may lead to renal bone disease. Your bones become brittle and painful and are more likely to break. Foods high in phosphorus include dairy products and processed foods.
- Eat enough protein. Dialysis puts stress on the body. That's why it is important to consume adequate protein. A "wasting away syndrome," or a loss of fat and muscle mass, is common in people on dialysis who do not eat properly. More protein is lost during peritoneal dialysis than hemodialysis. So, people on peritoneal dialysis need to consume even greater amounts of protein.
- Control your intake of high sugar and fatty foods if you are on peritoneal dialysis. The dextrose solution used

in peritoneal dialysis may cause weight gain and elevated triglycerides levels (fat in the blood). For this reason, you need to watch what you eat.

Diabetes, high blood pressure, heart disease, and other diseases also present dietary challenges. Our transplant nutritionist can help you design a healthy diet that meets your needs. If you'd like to meet with our transplant nutritionist, talk to your pre-transplant coordinator.

- Take any medicines that your doctor has prescribed, including insulin and diabetes medicines, if appropriate.
- Exercise on most days of the week—if your primary care doctor gives you the OK. Patients who exercise tend to recover better from transplant surgery. Exercise does not have to be hard—in fact, walking is one of the best exercises around.
- Keep your teeth and gums healthy. Brush twice a day, and floss once a day. Good dental care can help prevent gum infections. You should also see your dentist on a regular basis for checkups.
- Stop smoking, if you smoke. If you need some help, talk to your primary care doctor.
- Lose weight, if you need to. Depending on your body mass index (BMI), the surgeon may ask you to lose

some weight before you can get a transplant.

Figure 1, page 22, will tell you what your BMI is and whether you are overweight or obese. Our transplant nutritionist is happy to sit down with you to develop a diet that will help you lose any extra pounds.

- Get an annual flu shot each fall. Your primary care doctor may also recommend a pneumonia vaccine.

Stay in Contact With Us. Your pre-transplant coordinator will check in with you on a regular basis while you're waiting for your transplant. We hope that you will stay in regular contact with us, too. Be sure to call us with any questions or concerns. It's also **very, very** important that you notify us of any changes in your life, including:

- Any changes of address or phone numbers.
- Any major illnesses or changes in your medical condition, such as strokes, heart attacks, or infections.
- Any hospitalizations or surgery.
- Any blood transfusions.
- Any pregnancies.
- Any vacations you have planned.
- Any time you change your primary care doctor or dialysis center.
- Any change in your insurance.

Figure 1

		Normal										Overweight										Obese										Extreme Obesity									
		19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46	47	48	49	50	51	52	53	54				
BMI	Height (inches)	58	91	96	100	105	110	115	119	124	129	134	138	143	148	153	158	162	167	172	177	181	186	191	196	201	205	210	215	220	224	229	234	239	244	248	253	258			
		59	94	99	104	109	114	119	124	128	133	138	143	148	153	158	163	168	173	178	183	188	193	198	203	208	212	217	222	227	232	237	242	247	252	257	262	267			
	60	97	102	107	112	118	123	128	133	138	143	148	153	158	163	168	174	179	184	189	194	199	204	209	215	220	225	230	235	240	245	250	255	261	266	271	276				
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	62	104	109	115	120	126	131	136	142	147	153	158	164	169	175	180	186	191	196	202	207	213	218	224	229	235	240	246	251	256	262	267	273	278	284	289	295				
	63	107	113	118	124	130	135	141	146	152	158	163	169	175	180	186	191	197	203	208	214	220	225	231	237	242	248	254	259	265	270	276	282	287	293	299	304				
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	74	148	155	163	171	179	186	194	202	210	218	225	233	241	249	256	264	272	280	287	295	303	311	319	326	334	342	350	358	365	373	381	389	396	404	412	420				
	75	152	160	168	176	184	192	200	208	216	224	232	240	248	256	264	272	279	287	295	303	311	319	327	335	343	351	359	367	375	383	391	399	407	415	423	431				
	76	156	164	172	180	189	197	205	213	221	230	238	246	254	263	271	279	287	295	304	312	320	328	336	344	353	361	369	377	385	394	402	410	418	426	435	443				

Source: Adapted from Clinical Guidelines on the Identification, Evaluation, and Treatment of Overweight and Obesity in Adults: The Evidence Report.

Figure 1

If you are waiting for a deceased donor organ, we need to be able to reach you at all times of the day and night. Your pre-transplant coordinator will usually ask you for several phone numbers where she or he can reach you. For instance, you might give us your home number, your work number, your cell phone or pager, the number at your dialysis center, or a family member's number. If you don't have a cell phone or pager, you might want to consider getting one. Many organs come in the middle of the night. So, be sure to keep a phone by the bed.

When an organ becomes available, we only have one hour in which to reach you. If we cannot locate you during that time, we have to turn the organ down so that it can be offered to someone else.

Give Monthly Blood Samples. Patients who are waiting for a deceased donor organ will need to provide one to two tubes of blood once a month. That's because Gift of Hope needs to have fresh blood on file for you at all times in case an organ becomes available.

A test is also performed to assess your antibody levels. Your PRA, or antibody level, can vary from month to month. So, we need to check it on a regular basis.

Your pre-transplant coordinator or Gift of Hope will help you set up these regular blood tests. If you are on hemodialysis, you can have the blood samples taken at your dialysis

center. If not, then you can have the blood samples taken at a nearby doctor's office, laboratory, or hospital.

Get Ready for Your Hospital Stay and Recovery. As you'll learn in Your Transplant Surgery chapter, you can expect to stay in the hospital for 4 to 10 days, depending on the type of transplant you are receiving. Then, it will be several months to a year before your life gets back to "normal." The first year after a transplant is very full. In addition to recovering from major surgery, you'll have to adjust to taking new medicines. You will also be spending lots of time at the Post-Transplant Clinic. (See Life After Your Transplant chapter.)

Here are some things to think about as you prepare for this busy and stressful time:

- How can I get to the hospital on the day of my surgery? Who can drive me home? How can I get to the hospital for all my post-transplant visits?
- What do I need to pack to bring to the hospital? Patients who are waiting for a deceased donor organ may have as little as one hour to get to the hospital after they learn that an organ has become available. So, many patients like to have a suitcase packed and ready to go.
- Do I need to make any changes in my home so it's an appropriate place to recover after surgery? Who can come by to check on me during the first few weeks? Would it be better for me to stay at a family member's or friend's until I'm strong enough?

- Who will watch my children and/or pets while I'm in the hospital? Do I need to arrange for childcare so I can get to my post-transplant visits?
- For patients who work: What are my job's short- and long-term disability policies? How much time do these policies allow me to take off work with pay? How can I prepare my boss for my eventual leave? How can I help ensure my job will be there when I get back?
- Are my will and all my life insurance policies in good order?

If you live out of town, you will have many other preparations to make, including finding a place to live for a few weeks after you are discharged from the hospital. Your pre-transplant coordinator and the transplant social worker can help you find appropriate accommodations and transportation. Table 2, page 33, offers some additional advice.

Patients from other countries should contact UCH's International Health Services at 1-877-482-8318 (toll-free) for help arranging accommodations.

Watch Out for Your Mental Health. There will undoubtedly be times while you are waiting for a transplant when you will feel sad, frightened, worried—and a hundred other emotions. Please don't try to get through this time alone. Find someone to talk to, such as your

spouse, a close friend, a relative, a clergy person, or a counselor.

You should also consider coming to our quarterly support groups for transplant patients. These meetings are an opportunity to meet other transplant patients who know exactly what you're going through. Our transplant social worker can provide you with more information on these meetings.

It's also important to keep busy while you're waiting. The fuller your life is, the faster the time will pass. So, keep up with your hobbies, visit with family and friends, or get active in a community organization. But don't overdo it. It's especially important to give yourself time to recover between dialysis sessions.

Common Questions About the Pre-Transplant Period

TESTS AND EVALUATIONS

Q. What's the oldest you can be to receive a transplant?

A. We don't have an upper age limit. We base our decisions on a patient's overall condition rather than an arbitrary age limit. Older people are more likely than younger people to have major health problems that may interfere with the success of a transplant. But many people in their 60s and 70s are healthy enough to receive a transplant.

Q. I have type 2 diabetes. Is a pancreas transplant an option for me?

A. A pancreas transplant only helps when the pancreas does not produce any insulin—as in the case of type 1 diabetes. People with type 2 diabetes still produce insulin. But their bodies cannot properly use the insulin. So, a pancreas transplant would not help you.

DECEASED DONOR ORGANS

Q. Can I list with more than one transplant center?

A. All of the transplant centers in Illinois use the same local patient waiting list, which is managed by Gift of Hope. You only need to list with one transplant center in the local area. So, if you list with the University of Chicago Hospitals, you don't need to list with Northwestern, Rush, or another Chicago-area center—and vice versa.

However, you can list with a second or third transplant center outside of this area. For instance, you could list at the University of Chicago Hospitals and a transplant center in Wisconsin. If you did this, then you would be eligible for organs that become available both in Illinois and in Wisconsin. This may shorten the waiting time for some patients in need of transplant.

If you list with a second transplant center, you will probably need to go through a second set of pre-transplant evaluations. Before you pursue this, you should make sure that

your insurer will cover this second set of evaluations. Remember, too, that if you sign up with a transplant center far from your home, you will need to arrange for transportation and accommodations. After your transplant, you will need to return to your transplant center several times a week for months after your transplant.

Q. How long will I have to wait for a deceased donor organ? Is there any way to shorten the amount of time I have to wait?

A. The average wait time for kidney-only transplants is three to four years. Kidney-pancreas patients typically wait between one and two years. And pancreas-only patients tend to wait between one and two years.

Some patients may be able to shorten their waiting time by accepting a carefully selected organ from an older donor or another "expanded criteria donor." We will review this option with you during your pre-transplant evaluation.

Q. Do patients with a certain blood type have a longer or shorter wait than others? Do any other factors lengthen or shorten your wait time?

A. Your blood type can affect your wait time. Patients with blood type O or B tend to wait longer than patients with blood types A and AB. National statistics report the following average wait times by blood type:

- Blood type O: 1,248 days
- Blood type B: 1,501 days
- Blood type A: 592 days
- Blood type AB: 350 days

Please remember that these are only average wait times. Your personal experience could be very different. UNOS may find you the perfect match a few days or months after you are listed.

Why do people with A and AB tend to have a shorter wait? Blood type AB is compatible with all blood types. And blood type A is fairly common in the U.S. population. Patients with these blood types have greater chances of finding compatible donors quicker. In comparison, a person with blood type O is only compatible with one blood type: O. So it is harder to find a compatible donor for a person with this blood type.

Your PRA or antibody level can also affect your wait time. Patients with a high PRA usually have to wait longer for a compatible organ than patients with a low PRA. Why? Because a high PRA means a patient is likely to reject organs from a high number of donors. So, it's harder to find a compatible donor for these patients.

UNOS recently adopted new policies so that a person's race is less likely to affect wait time. Historically, African Americans, Hispanic Americans, and Asian Americans have tended to wait longer for donor kidneys than whites. The reason: HLA matches tend to be better when a patient is matched with a donor of the same race. However, there are fewer minority donor organs available than white donor organs. So, minorities have had to wait longer for a good HLA match. The

new policies hope to fix this problem by relaxing the HLA matching criteria. Research now shows that HLA matching does not have to be perfect for a transplant to be successful. Minority patients will now be considered for more of the white donor organs that become available.

Q. I am on the waiting list for a deceased donor organ. But now I have to move to another state and will be changing to another transplant program. Will I have to start the waiting all over again? Or can I get my waiting time transferred to my new hospital?

A. You can get your waiting time transferred. Talk to your pre-transplant coordinator. She or he will work with your new transplant center to arrange this.

Q. What happens if I get sick? Will I be taken off the waiting list?

A. If you have a significant infection or other illness, you will be placed on the inactive waiting list until you can be safely transplanted. Once you are better you will be put back on the active waiting list. However, you won't lose the "waiting time" you already put in.

Q. Is there any way to know when I'm getting close to the top of the waiting list?

A. One way is to compare how long you've been waiting with the average wait time. For instance, the average wait time for a deceased donor kidney is three to four years. When you've been waiting about this

amount of time, then you're probably near the top of the waiting list.

Your pre-transplant coordinator may also give you a "heads-up" when she or he sees your name appearing near the top of the list that Gift of Hope provides whenever an organ becomes available.

LIVING ORGANS

Q. Can I have more than one donor tested at the same time?

A. If you have more than one potential donor in mind, we can perform two blood tests—a blood type test and an HLA antigen test—on each of the donors. The results will tell you which donor might be the best match. Then, that donor can arrange for all his or her medical evaluations and tests.

Table 1. UCH's Transplant Process— in a Nutshell

THE PRE-TRANSPLANT PERIOD

1. Attend a group informational meeting, if you have not done so already. For information on these meetings, call (773) 702-9287. If you have identified a potential living donor(s), you might ask them to attend this meeting with you.
2. Undergo a series of medical tests and evaluations. Determine whether your insurance benefits will cover the costs of the transplant—including medicines you

will need to take after you receive a new organ(s). (See Financial and Insurance Issues chapter for more information on finances.)

3. Meet one-on-one with transplant staff to discuss your transplant options.
4. Wait for your surgery:
 - Patients undergoing deceased donor transplants are put on the national and local waiting lists. Depending on the organ(s), you may have to wait one to five years for a deceased donor organ to become available. During this time, you will need to have regular blood tests taken and stay in close contact with your pre-transplant coordinators. Once an appropriate organ(s) is found for you, you will need to get to the hospital very quickly for surgery.
 - Patients undergoing living donor kidney transplants—and their healthy donors—will need to undergo additional medical tests to determine if their organs are a good match. This process can take several weeks to months. If the organs are a good match, a surgery date will be scheduled. Donors undergo surgery on the same day as the transplant patients.

THE SURGERY AND HOSPITALIZATION

5. Arrive at the hospital for surgery. You may need to undergo some additional tests and evaluations before you're wheeled in for surgery.

6. Undergo and recover from surgery. Most transplant patients stay in the hospital four to 10 days, depending on the organ(s) transplanted. Living donors are usually discharged sooner, after two to three days. Before going home, transplant patients receive extensive education about the medicines they will need to take and other self-care habits they will need to adopt.

POST-TRANSPLANT PERIOD

7. Return to the hospital's Post-Transplant Clinic on a regular basis. We need to keep a close watch on you for a full year to make sure your transplant is going well. For the first few months after your transplant, you will probably need to come back to the clinic a few days a week. You will need to have various labs done to make sure your body is accepting your new organ. As your condition stabilizes, your clinic visits will decrease.
8. Return to the care of your regular doctor. You will need to take anti-rejection medicines for the life of your transplanted organ.

Table 2. Tips for Out-of-Town Patients

The following suggestions are provided by an out-of-town patient who received a transplant at the University of Chicago.

Your Home and Family. Since you will be gone for up to three months, be prepared to have

someone keep an eye on your residence and to pick-up and forward your mail. Even though you are gone, life goes on and so do your obligations (bills). With the residence, do not forget about your pets as well.

Depending on the time of year, and if you have children, how will you take care of school? Will the kids come with you or will they be staying with family and friends? I know that these are only questions, but it is better to be thinking about them now and coming up with answers while you have time to plan. The day of the call for a transplant is NOT the time to handle these items. What worked best for us is to get the family together and list out all these items on paper and have each family member assigned specific tasks.

Packing. What to bring with you is going to be influenced by the time of year you are dealing with. Clothing is not the only thing you will need to consider when you are packing. Depending on where you will be staying, you will have access to different setups for cooking, cleaning, and laundry. The following are some suggestions that you should consider regardless of the season and the residence.

Whatever the season, comfort is key. While you are in the hospital, sweats, jeans, shorts, or any other comfortable clothing works well. For the patient, during the first week or so, underwear and socks are about all that is needed. As tubes and IV's are removed, pajamas, robe, and slippers are nice to have. Also, remember a comfortable pair of shoes. As

your strength improves, the doctors will want you to do plenty of walking.

When you leave the hospital be prepared to bring or buy:

- All food and personal care items
- Blood pressure cuff (if already using one)
- Glucometer and supplies
- Medicines
- Hose adapter for washing hair (no showers initially)
- Bathroom scale
- Loose-fitting clothes until incision is healed
- Insurance card and pharmacy information
- Long-distance calling cards
- Personal address and phone books/stamps
- Map of Chicago

Are You Ready for the Call? When the call comes for your transplant, you will need to get to Chicago as quickly as possible. Make sure you know in advance who to contact to make your travel arrangements. Have your bags "pre-packed" as you get closer to the call. By having things in order prior to the call, this time will be less stressful. And don't forget, who will get you to the airport?

One Patient's Pre-Transplant Experience

Carmen is a 68-year-old recipient of a deceased donor kidney. Below, Carmen shares what she went through while waiting for her transplant.

When I was diagnosed with end-stage kidney disease, my doctors put me on hemodialysis three times a week. About three months after I started dialysis, I called the University of Chicago Hospitals for information about getting a kidney transplant. The hospital was approved by my insurance, and it was the closest transplant center to my home in Indiana. I also called a kidney transplant program in Wisconsin because some people said I would have a better chance of getting a kidney if I got on the waiting list at two transplant centers in two different states.

So, I had to complete the pre-transplant tests and evaluations for both hospitals. There were lots of tests. They tested me for AIDS, cancer, and all kinds of diseases. They wanted to make sure that once I had the transplant and I started on the immunosuppressant drugs, I would not start getting sick or develop another disease. They wanted to make sure I was healthy other than having kidney disease.

I had some of the tests, such as a colonoscopy and a Pap smear, done near my home. Then, I spent an afternoon at the University of Chicago getting some of my other tests and evaluations done. The University of Chicago was able to coordinate some of the tests and evaluations with the Wisconsin hospital.

About a month after I went to the University of Chicago for tests, I found out that I had been accepted into the Hospital's kidney transplant program. Then, I was placed on the waiting list for a deceased donor kidney.

I did try finding a living donor. I have two brothers, but they both have high blood pressure. So they could not donate. A few people through my church offered to give me their kidney. But for various reasons, they could not donate. For instance, one man who volunteered forgot he was taking blood pressure pills.

While I was waiting, I tried to stay as healthy as possible. I followed whatever directions the doctors and nurses gave me. I didn't even think of skipping any dialysis sessions. Even if there was a snow storm, I would make every effort to go. And I was very good about not drinking too many fluids. After I got my transplant, one of my friends teased me, saying 'Oh, you were lucky because you followed all of the rules'."

I went on a vacation to California for several months to get away from the cold winter here. I was a little worried about being away for so long in case a kidney became available. So, I called my pre-transplant coordinator to see if it was OK for me to go. She told me that it was probably too soon to expect a kidney. So, I went on vacation without worrying.

After about two years of waiting, I was prepared to be on dialysis for life. I felt pretty good as long as I went three times a week. But it was not a pleasant experience. Some of those technicians were not always skillful in getting the needles in. It could really be a painful procedure. I tried to keep my hopes up that I would receive a kidney.

And then, suddenly, two years and eight months after I was put on the waiting list, I got a phone message from my pre-transplant coordinator at the University of Chicago Hospitals. I was surprised when I got the recording. I had just come home from church and here was this recording from my pre-transplant coordinator. She said, 'Call this number because we have a kidney for you'."

I didn't know what to do at first. I was so excited. First I called my neighbor, who is a very good neighbor. She's always taking me places when I cannot drive myself. Luckily, she was home and could drive me to the hospital. But she wasn't too sure where to go. So, I called another friend who had accompanied me to the University of Chicago Hospitals before. And, thankfully, she agreed to come along, too.

My pre-transplant coordinator said we had to be at the hospital within two hours. I quickly put some stuff I thought I would need in my suitcase. I had packed for the hospital when I first signed up for a transplant. But that was over two years ago, and along the way, I had slowly taken stuff out of the suitcase. So I had to throw stuff into the suitcase quickly. And then my two friends and I left for the hospital.

Carmen's transplant surgery and recovery went very well. She thanks all of the people who prayed for her recovery. Carmen has this advice for people who are waiting for a transplant: "Just keep up your hopes and, above all else, keep up your health."

A Living Organ Recipient's Experience of the Pre-Transplant Experience

Mark, a 38-year old man with type 1 diabetes, kept the following journal from the time he learned that he had kidney failure till the time his transplant surgery was scheduled. Mark's brother Jeff gave him one of his kidneys. (Only entries related to his transplant are included.)

Date	Comments
Mar 8	Regular 3-month check up with my doctor. Blood test results as follows: A1C = 6.2, Creatinine = 6.8, BUN = 73. Instructed to see nephrologist soon.
Apr 9	Visit with nephrologist. Blood tests as follows: Creatinine = 7.5, BUN = 72, Hemoglobin = 11.6, and white cells = 15.66K. Dr. explains dialysis treatments. We decide peritoneal dialysis would be best for me. Dr. refers me to surgeon to insert the peritoneal catheter.
May 8	Placed referral for organ transplant with insurance.
May 10	My brother Jeff and sister Dawn tell me they are both willing to donate a kidney to me.
Jun 14	Received letter from my insurer that my transplant evaluation has been approved at the University of Chicago Hospitals.

Jun 18	Spoke with pre-transplant coordinator at the University of Chicago Hospitals today. She scheduled me for an initial consultation with the medical staff on July 10. Also scheduled my sister Dawn, brother Jeff, and I for a Kidney Education meeting on July 9. She's sending me info via mail on both.
Jul 10	Met with transplant surgeon and pre-transplant coordinator for the first time. Gave me a stress test, echocardiogram, blood test, and chest x-ray.
Aug 6	Dawn, Jeff, and I give blood for organ match compatibility.
Aug 9	Was informed today that Dawn and Jeff have compatible blood types for organ donation. We have scheduled a genetic test for Monday 8/19/01 at 10 AM.
Aug 16	I have a scheduled meeting with the cardiologist at 9:45 am today. Also, I am to meet with the social worker at 11 am.
Aug 18	Dawn, Jeff, and I go to the University of Chicago for a genetic blood test.
Aug 28	My pre-transplant coordinator has informed us that Jeff matched 6 out of 6 criteria for organ donation. We are proceeding with the required tests for Jeff.

Sep 4	Jeff started the transplant evaluation process. He had blood tests, urine test, chest x-ray, and met with the social worker today.
Sep 11	Jeff has more evaluation tests today including meeting with the kidney specialist, a glucose tolerance test, and a 24-hour urine specimen.
Oct 2	My final test before surgery, draw blood and meet with the doctors.
Oct 3	Jeff goes for CAT scan and meets with doctors.
Oct 8	Transplant surgery scheduled for 6 a.m.

Mark's and Jeff's surgeries went fine. Mark is now awaiting a second transplant surgery—a deceased donor pancreas to treat his type 1 diabetes.