Life After Your Transplant

Welcome to the start of your new life post-transplant. A lot of things may already be changing for the better. Within weeks to months of leaving the hospital, most patients find that they have more energy. And you’ll have more time to enjoy all this energy because you won’t need to spend hours a week in dialysis, monitoring your diabetes, or both.

But life after a transplant, particularly during the first several months, can be overwhelming and intense. You will probably have dozens of questions about how to take care of yourself and your new organ(s). You may wonder how to care for your surgery incision or keep track of all of your medications. You may be concerned about getting an infection or rejecting your transplant.

Don’t worry. There is a lot to learn and adjust to after a transplant. But we are right here to help you—24 hours a day, every day. After you are discharged from the hospital, you will be visiting the Post-Transplant Clinic on a regular basis. Plus, the post-transplant nurses, who will be helping to manage your post-transplant care, are always reachable by phone or pager for urgent problems.

This chapter provides an overview of what you can expect after a transplant. First, you will learn about possible problems that can occur—and how we prevent and control these problems. Then, you will find out
what you can do to protect your new organ and your health. Every patient's experience is somewhat different depending on his or her health, age, medicines, and other factors. So, please talk to us if you have any questions or concerns.

**How We Control Potential Problems**

**IN SHORT**

Here are some problems that can happen after a transplant:

- Your body may reject, or attack, your new organ.

- You may get an infection, which will need to be evaluated and treated.

- Your medicines might cause some problems. For instance, you might have an upset stomach or diarrhea.

We will keep a close eye on you. We will give you medicine to help prevent and treat these problems.

Thanks to recent advances in anti-rejection medicines, our transplant patients have a lower risk of organ rejection, infection, and other problems than they did just five years ago. Our transplant doctors and nurses are experts at pinpointing the best medicines for you—given your age, health, transplant history, etc. We have also discovered better ways of detecting problems early on so that we can treat them quickly before your new organ or your overall health is harmed. And, every day, we are uncovering even better ways to prevent and treat rejection, infections, and other problems that develop after transplant. You have a very good reason to be optimistic about your future.
Below are some of the common problems that can develop after a transplant—and what we do to prevent and control these problems. A lot depends on you, too. We need you to work with us closely and comply with our recommendations. See “How to Protect Your Health—and Your New Organ,” page 12, for specific health advice.

**Organ Rejection.** As you’ve learned in previous chapters, rejection occurs when your body’s immune system attacks your transplanted organ. The type of rejection that we’ll be concerned with most for the first several months after your transplant is *acute rejection*. Acute rejection occurs when your body is still adjusting to your new organ(s) and your immune system decides to launch an assault on your new kidney and/or pancreas. Acute rejection may occur at any time after a transplant. But most episodes occur in the first few weeks to six months after a transplant.

Because of advances in anti-rejection medicines, *acute rejection* is becoming less common. Many patients never experience an episode of acute rejection. But about 20% of patients will have a rejection episode during the first few months. So, you should prepare yourself for the possibility of a rejection episode—but don’t fear it. A rejection episode simply means that your body is starting to attack the transplant. It does not mean that your new organ is going to be lost. More than 95% of acute rejection episodes can be successfully treated and reversed.

The earlier an acute rejection episode is treated, the better the chances of reversal. Rejection is
almost always detected through the blood tests and other lab work that you will have done at the Post-Transplant Clinic. These tests are very sensitive and can detect changes in your body that signal the early stages of rejection long before you would "know" something is wrong. In fact, few patients experience any symptoms when they begin to develop acute rejection. So, your clinic visits and lab tests are very important in detecting rejection.

The exact lab tests you will have during clinic visits will depend on whether you had a kidney-only, pancreas-only, or combined kidney-pancreas transplant. Your lab tests may include:

- Blood tests to check anti-rejection drugs levels.
- Kidney function tests, including creatinine and blood urea nitrogen.
- Urinalysis.
- Glucose test.
- Blood tests to monitor levels of important pancreatic enzymes.

If we suspect a rejection episode, we may do a biopsy. A biopsy allows us to look at a tiny piece of your kidney or pancreas under a microscope to see if the problem is rejection or something else.

Kidney biopsies are performed on an outpatient basis in the Post-Transplant Clinic. It's a minor procedure. So, there's no reason to be afraid. First, you will be given a local anesthesia to numb the area to be biopsied. Then, the doctor will insert
a special biopsy needle through your skin to remove two or three tiny pieces of organ tissue. You will have to lie still for a period of time. We will check you and your urine for signs of blood before you leave. You should be able to go home after a biopsy. Our kidney pathologist then examines these specimens under a microscope to determine if rejection or any other problem is present. Because the University of Chicago Hospitals has a pathology lab on-site, we usually can review the biopsy and call you with the results within 24 hours.

When acute rejection does occur, it is important to start treatment as soon as possible to prevent loss of the transplant. Treatment depends on the severity of rejection. Some patients only need a change in their anti-rejection medicines. But others need to be admitted to the hospital or come to the clinic each day for a short time to receive high doses of medicines intravenously.

Again, over 95% of acute rejection episodes are successfully reversed. However, you should know that each episode of acute rejection could cause some damage to your transplanted organ(s). It is best to avoid any rejection by taking your medicines as prescribed and getting your labs checked regularly.

It is uncommon for acute rejection to occur after you’ve had your new organ(s) for a year —unless you stop taking your anti-rejection medicines. In fact, non-compliance with medicines is the number one reason that people have acute rejection.
rejection after the first year. This is why it is vital for you to
never stop taking your anti-rejection medicines unless your
transplant doctor or nurse tells you to do so.

A different type of rejection, called *chronic rejection*, may
become a problem years after you get your transplant. This
is sometimes referred to as *chronic allograft nephropathy* in
kidney transplants. Chronic rejection develops slowly over a
period of months or years. The organ begins to wear out and
become scarred, gradually losing its ability to work properly.
Chronic rejection is the reason why some patients whose
transplants work well for many years eventually have to go
back on dialysis or on insulin.

Doctors and researchers at the University of Chicago
Hospitals and elsewhere are working hard to understand
exactly what causes chronic rejection. We know that people
who have acute rejection are more likely to develop chronic
rejection. The types of medicines that you take to prevent
rejection may also play a role. We are also making progress
in finding ways to identify and treat patients who are likely
to experience chronic rejection so that we might prevent it
from happening.

Most patients have good function of their transplanted
organ(s) for many years. In our experience, nearly 85% of
patients whose transplanted pancreas or kidney were
working well after a year go on to have at least five—and
often many more—additional years of kidney and
pancreas function.
Infections. Without anti-rejection drugs, organ transplants would currently be impossible. But these medicines do have their downsides, including an increased risk of infection. Anti-rejection drugs act by weakening your body’s immune system so that it has less power to attack your new organ(s). But a weakened immune system also means your body has more trouble warding off infections. Your immune system no longer has 100% of its “soldiers.” Your body still has a good ability to fight bacterial infections, but you may be more likely to get certain viruses and other infections.

Your risk of infection will be highest during the first month or two after your transplant. Because your risk of acute rejection is also high during this time, you will probably be taking fairly high doses of anti-rejection medicines for the first few months to prevent rejection. The higher the doses of anti-rejection medicine, the weaker your immune system—and the higher your risk of infection. To help prevent infections during these first few months, we will prescribe anti-viral medicines and other drugs to fight off infections, as appropriate.
The doses of anti-rejection medicines that you take will gradually decrease as your risk of rejection goes down. Within a year of transplant, you will probably be taking much lower doses of anti-rejection medicines than you are right after transplant. As the doses of anti-rejection medicines are lowered, your risk of infection also goes down. Eventually, you will no longer need to take anti-viral drugs and other medicines to prevent infections.

It’s very important that you tell us as soon as you develop a fever or other signs of infection (see Table 1, page 36). Because you are on anti-rejection medicine, you may have more trouble fighting off infections than a person not taking these medicines. A relatively minor infection may become serious. We will be more likely to admit you to the hospital for a relatively minor problem, such as the flu or dehydration, than the average person. We do this to prevent more serious problems from developing and to make sure that you get adequate amounts of anti-rejection medicines in your body.

<table>
<thead>
<tr>
<th>What Can You Do to Control Infection?</th>
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<tr>
<td>• Take precautions against infections</td>
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<td>• Be faithful about your lab tests and clinic visits</td>
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<tr>
<td>• Take your medicines as prescribed</td>
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<td>• Pay attention to your health</td>
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<td>• Commit to a healthy lifestyle</td>
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**Other Health Problems.** In addition to raising your risk of infections, anti-rejection medicines can cause certain side effects, including:

- high blood pressure.
- heartburn.
- type 2 diabetes (high blood sugar).
- acne.
- diarrhea.
- constipation.
- changes in hair growth.
- weight gain.

Most of these side effects are dose-related. In other words, the higher the dose of anti-rejection medicines you are on, the higher your risk of side effects. Our transplant doctors try to reduce side effects by prescribing the smallest possible doses of anti-rejection drugs. One advantage of using several anti-rejection medicines is that lower doses of

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**What Can You Do to Control Other Health Problems?**

- Get regular health exams and screenings
- Take your medicines as prescribed
- Commit to a healthy lifestyle
- Don't smoke
- Drink alcohol only in moderation (when your doctor says that this is okay)
each medicine can be used. In addition, some patients may benefit from switching to a different medication, but this should only be done under the direction of the transplant team.

Even so, you may have some side effects for the first few months or so after your transplant. As discussed above, many patients take fairly high doses of anti-rejection medicines during this period to prevent rejection. But the transplant team will gradually lower your doses of anti-rejection medicines as your risk of rejection goes down. Many side effects disappear or become minimal once you are taking lower doses of anti-rejection medicines.

**What about long-term health problems?** Does having a transplant or taking anti-rejection medicines increase your risk of heart disease, cancer, or other serious health problems?

As with all patients, you should monitor your cholesterol, especially if you have a personal or family history of heart disease. Some anti-rejection medicines can raise your cholesterol or triglyceride levels. We will keep an eye on these levels and adjust your medications as necessary. Many patients will start on a cholesterol-lowering medication when they go home from the hospital. This is often used, even if the cholesterol is normal, because there is good evidence that it keeps transplanted kidneys healthier and may provide additional protection against rejection.
Patients who are taking medicine to suppress the immune system (like anti-rejection medicine) have a higher chance of developing certain types of tumors. In particular, skin cancers are more common, especially if you are exposed to the sun a lot. This is why we will be warning you about going out in the sun for long periods of time without appropriate sunscreen or clothing. We will also encourage you to see a dermatologist on a regular basis so that any problems can be diagnosed early and taken care of. Fortunately, most skin cancers are easily treated with simple removal, if they are detected and treated early.

There is a small risk (1 to 2 out of 100) that a transplant patient might develop an abnormal growth of lymph node tissue, which is a type of lymphoma or lymph node tumor. This may develop months or many years after the transplant. It is more common if you have required a lot of medication to prevent or treat rejection episodes. Fortunately, this lymphoma can often be treated by simply decreasing the amount of anti-rejection medication that you are taking. If that doesn’t work, however, it may require other types of treatments, including chemotherapy. We will work with you and your doctors to watch for this problem after a transplant.

Underlying health problems, as well as some of your medicines, may also contribute to osteoporosis (thinning of the bone) and type 2 diabetes. Your transplant doctor may prescribe medicines to limit bone loss. You may also need regular tests to check your bone density. Regular exercise and maintaining a healthy weight can help prevent—and control—both osteoporosis and type 2 diabetes.
Depending on your age, gender, and medical history, you will need to get various cancer screenings on a regular basis, such as mammograms, pap smears, and prostate exams. You should talk to your primary care doctor about scheduling these screenings.

**How to Protect Your Health—And Your New Organ**

**IN SHORT**

To prevent problems with your new organ:

- Come to the clinic when we ask you to.
- Take your medicines just like we tell you to.
- Take it easy for about six weeks after your transplant.
- Tell us if you feel sick or “funny.”
- Wash your hands a lot. Stay away from sick people.
- See your other doctors for check ups.
- Eat food that is good for you.
- Get some exercise.
- Follow other advice that we give you.

The success of your transplant depends, in many ways, on your willingness to be an active member in your health care. You will have a higher chance of keeping your transplanted organ for many years if you comply with all of our advice.
Be Faithful About Your Clinic Visits and Lab Tests. For the first several weeks after you are discharged from the hospital, you will need to come to the Post-Transplant Clinic one to three times a week—on Monday, Wednesday, or Friday. (See Table 2, page 39, for clinic hours and location).

Each clinic visit will take as long as two to four hours. First, you will have your blood drawn and, if necessary, provide a urine sample. Then, you will get weighed and have your temperature and blood pressure taken. Once the results of your lab tests are ready, you will meet with a transplant surgeon, nephrologist, and/or post-transplant nurse. We'll give you a medical check up, talk about how you are feeling, go over the results of your lab work, and discuss your medications.

There will be plenty of time during clinic visits to ask the doctors and post-transplant nurses any questions that you have about your medicines, wound care, diet, or other issues. We are concerned about your whole health—not just the health of your new organ. So don't hesitate to ask about health issues that are not related to your transplant. If you'd like, you can invite a family member or friend into the exam room with you. Sometimes it helps to have a second pair of ears.

Be sure to bring a list of the medicines that you are taking. Also, please bring any information that you were asked to record, such as your temperature or urine output. (See “Pay Attention to Your Health,” page 21.)

Please note that some of the anti-rejection drugs, such as tacrolimus (Prograf), cyclosporine
(Neoral), or sirolimus (Rapamune) should be taken after—not before—your blood is drawn at clinic. So be sure to read all the directions for your medicines very carefully. You may need to bring some of your drugs with you to take while you're at clinic.

Once we're confident that your new organ(s) is working well and your risk of rejection is lower, you can cut back on the number of times you come to the clinic. Often patients can have their labs drawn closer to home at this point, too.

If your condition is stable six months to one year after your transplant, you will no longer need to come to the Post-Transplant Clinic on a regular basis. You will then go back to your regular doctor for all your primary health needs. For example, you may return to your internist, nephrologist, or endocrinologist. However, we will still be overseeing your transplant care. We want to be kept informed of your progress, especially any problems that you might encounter:

- You will need to get lab tests done once a month at a local hospital or lab for as long as your transplant is functioning. If you or the lab provides us with the lab results, we will review them and call you or your physician if we detect any problems.

- If you develop a cold or the flu, you should have your labs checked weekly for a minimum of two weeks to be sure that you do not develop any rejection. This is true for as long as you have your transplant.
• We would like to see you once a year at the Post-Transplant Clinic for a check up and to see if there is anything that might be changed to improve your health or the health of your transplant.

• We encourage you to call us—and have your other doctors call us—with any questions or concerns.

If you do not live in the Chicago area, you should plan on staying in the area for as long as three months after you are discharged from the hospital. As discussed in Before Your Transplant chapter, we can help find temporary housing for you and your family during this period. After you go home, you will need to get lab tests done at a local hospital or lab on a regular basis so that we can continue to monitor your condition.

**Take Care of Your Surgical Wound.** To ensure that your surgical wound heals properly, your sutures and/or staples will need to stay in place for 14 to 21 days after you are discharged from the hospital. The sutures/staples will be removed during one of your appointments at the Post-Transplant Clinic.

• Clean the incision twice a day, following the instructions given to you in the hospital.

• Be sure to wash your hands with soap and water before and afterwards.

• Gently remove the dressing from your wound. If the bandages are stuck, wet the dressing with water. Wait a few minutes before trying to remove it.
• Clean the incision with rubbing alcohol, then with the Betadine medicine that was prescribed for you.

• Cover the wound with fresh dressing, if needed. You might want to cover your wound with a light dressing so that your clothes will not pull on the staples or sutures, but this is up to you.

• Call the post-transplant nurses if you notice any redness, swelling, drainage, increased warmth, or other troubling symptoms around your incision.

After you leave the hospital, it is okay to take a shower, even with staples or sutures. Just pat the area dry afterwards. You should avoid sitting in the bathtub with the sutures or staples. If you have an IV catheter or a drain (tube), you may need to keep those dry.

When your sutures and/or staples are removed, a doctor or nurse will tell you if and how you need to continue caring for your wound.

Get Your Ureteral Stent Removed, If Needed. During kidney transplant surgery, the surgeon had to connect your bladder to the donor kidney's ureter, which is a tube that drains urine from the kidney to the bladder. During this step, the surgeon may have placed a **stent**, or tiny tube, in the donor's ureter and into your bladder. This stent helps keep the ureter open until it heals, avoiding leaking or narrowing of the connection.

Once your body heals after surgery, this stent needs to removed. This outpatient procedure is usually performed
four to six weeks after your surgery in the University of Chicago Hospital’s Urology Clinic. We will arrange the appointment for you. This is not a big deal and does not require anesthesia.

**Return to Normal Activities—Gradually.** It will take about six weeks for your incision to heal substantially. Avoid lifting anything heavier than 10 pounds or so for the first two to three months after your surgery so as to avoid developing an incisional hernia (weakening of the muscle wall). You may gradually increase your activity once you leave the hospital. Listen to your body. If an activity is uncomfortable, back off and wait a while longer before resuming that activity. Here are some other guidelines:

- **Driving:** You may resume driving a car three to five weeks after surgery, if you are not having pain and can operate a vehicle safely. Painkillers can affect your ability to react properly when driving. So you should not drive if you are taking anything stronger than acetaminophen (plain Tylenol, for example).

- **Moderate-paced activities and exercise:** As soon as you are discharged. In fact, we encourage you to stay active to prevent your muscles from weakening and to improve your breathing. Walking is an excellent way to build up your leg strength.

- **Vigorous activities and exercise:** Wait six weeks after surgery before trying to run, swim, or ride a bike.

- **Work:** Unless your job involves heavy lifting or other activity, you may return to
work as early as three or four weeks after transplant. If your job is very stressful or physically hard, you may need to talk to your supervisor about working fewer hours or taking on different duties until you completely recover.

• Sexual activity: It’s safe to resume sexual activity about two to three weeks after surgery, if you are comfortable doing so. Both men and women should expect to be fertile after a transplant. Because of the medications you are taking and for other reasons, it is important for both male and female patients to protect against pregnancy in the months following a transplant. Please feel free to discuss this with us.

By ten to 12 weeks after surgery, you should be able to do any activity that you would like to. But play it safe: Check with a post-transplant nurse or doctor first.

**Take Your Medicines as Prescribed.** After your transplant, you will need to take a number of different medicines—some for life and others for a short time:

• Anti-rejection medicines. Most patients take two or three anti-rejection drugs, which help prevent rejection. The transplant doctors determine the best combination of anti-rejection drugs for you based on many different factors, including your age, the type of donor you had, and your other medical problems. You will need to take anti-rejection medicines every day for as long as your transplanted organ functions.
The doses may be fairly high for the first few weeks to prevent rejection. But then the transplant team will gradually lower the doses of these drugs.

- Drugs to prevent infections, such as antibiotics, anti-viral, and anti-fungal medicines. You will need to take these medicines, as prescribed, for a few weeks or months after your transplant to help prevent infections. Once your risk of infection is lower, you will only need to take these medicines when you develop an infection.

- Various drugs to prevent or relieve side effects from anti-rejection medicines. For the first few months after your transplant, your anti-rejection medicines may contribute to high blood pressure, water retention, high blood levels of potassium, and other side effects. Each patient responds differently to anti-rejection medicines. So you may or may not have these reactions. Medicines are available to relieve serious side effects. For instance, you may need to take high blood pressure pills. You may also take a medicine to lower the level of potassium in your blood, and a pill to prevent stomach ulcers. Once your doses of anti-rejection medicines are lowered, and as your kidney function improves, you may no longer need to take all or any of these additional medicines.

- Medicines to treat other problems that you may have: Although a transplant will improve your overall health, you may still have other health problems that will need
to be treated. These health problems do not go away with a transplant. You will have to continue to take medicines to treat heart disease, high cholesterol, thyroid disease, diabetes, or other problems that you may have.

The number and variety of medicines you need to take can seem overwhelming at first. And each medication comes with its own set of instructions. For instance, some need to be taken twice a day, but others need to be taken four times a day. How can you keep track of all these medicines—and make sure you take them all as directed?

Don’t worry. There are plenty of people here to help you. Before you leave the hospital, the transplant pharmacist and inpatient transplant nurse will sit down with you and help you understand all the ins and outs of the medicines you need to take. You will also receive a “medication sheet” while you’re in the hospital that will tell you at-a-glance when to take each medicine each day. We also ask that you bring all your medicines to the Post-Transplant Clinic for your first few visits. The post-transplant nurses will answer any questions you have about your medicines, and double check that you are clear on when and how to take each drug. Finally, you can call the post-transplant nurse on call (773-702-6338) at anytime whenever you have a question about your medicines.

It is extremely important that you take your medicines as directed and at the proper time. If you don’t, rejection could occur. You will hear us say over and over again: Never stop
taking your medication or change your doses unless your transplant doctors or nurses tell you to do so.

Finally, do not take any other medicines or herbal supplements, including over-the-counter remedies, unless you check with us first. Some medicines and herbs might cause damage to your transplant or interact with your anti-rejection drugs so that they become less effective. Many common medicines cause problems in transplant patients. These include non-steroidal anti-inflammatory drugs (NSAID), such as ibuprofen or naproxen. Many over-the-counter NSAIDs are sold by their brand names (for example, Motrin, Advil, Nuprin, and Aleve). Also, some antibiotics, such as erythromycin and azithromycin (Zithromax) can drastically alter the level of some anti-rejection medicines. Please check with us before taking these medicines.

(See Your Transplant Medicine chapter for additional tips on managing all your medicines.)

Pay Attention to Your Health. How you feel is not always the best sign of how your new organ is doing. You may feel perfectly fine. But then your labs show us that something is wrong.

However, your body can send out important signals. For instance, a fever may signal an infection or rejection. That’s why it’s important to listen to your body, and pay attention when you’re not feeling well. (See Table 1, page 36, for signs of rejection and infection.)
We recommend that you keep tabs on the following three things—especially for the first few weeks after your transplant. Use the post-transplant tracking sheet (see Figure 1, page 41) to record the results:

- **Your temperature.** Take your temperature two times a day for the first two weeks following surgery. Take it once in the morning when you wake up and once again in the evening. Call a post-transplant nurse whenever your temperature is greater than 100 degrees Fahrenheit (38 degrees Celsius). After the first few weeks, you only need to take your temperature if you have a cold, if you have chills or feel feverish, or if you do not feel well.

- **Your weight.** Weigh yourself each morning before breakfast on the same scale. This is especially important to do for the first few weeks after your surgery. But it's a good idea to weigh yourself regularly for the life of your transplant. If you notice a sudden increase in your weight (more than three or four pounds at once) call a post-transplant nurse. Sudden weight gains may signal a kidney that is not working normally.

- **Your fluid intake and output.** For the first two weeks following your transplant you should:
  
  - measure and record how much you drink.
  
  - measure and record how much you urinate.

Before you leave the hospital, you will be given measuring containers so you can track how much you drink and how
much you urinate. Occasionally, you might go home with a drain, or a small tube that drains excess fluid from the area where your transplant was placed. You will be taught how to empty this each day and record the volume of the fluid. Usually this tube does not have to stay in more than a few days. Your intake of water, juice, and other fluids should be more than your urine output, unless your body is carrying a lot of excess water. We recommend that most patients drink at least 2.5 to 3 liters (80-100 ounces) of fluid a day. Drinking a lot of fluids will help prevent dehydration and helps your kidney function properly. Call a post-transplant nurse if you notice a problem. After the first couple of weeks, you will probably no longer need to measure your fluid intake and output. But you should pay attention to how much you drink and whether you’re urinating a normal amount. (See “Commit to a Healthy Lifestyle,” page 27, for more tips on fluid intake.)

In addition, if you have problems with your blood pressure, it is useful to measure your blood pressure at home once or twice a day. This value may be more accurate than your blood pressure reading during clinic. We can help you get a blood pressure cuff for you to use at home when you are discharged.

**Take Precautions Against Infections.** One of the best ways to prevent catching an infection is to wash your hands often. Many infections are spread when you touch
your mouth, nose, or eyes with dirty fingers that are carrying germs. It’s especially important to wash your hands:

- before eating
- before and after using the bathroom
- before and after cleaning a wound or your surgical incision
- before changing your contact lenses
- before and after preparing food, especially raw meat, poultry, or fish
- after shaking hands with a large number of people (for example, after church or a meeting).

How you wash your hands is as important as how often. You should wash your hands with warm water and soap for about 15 to 20 seconds. Regular soap is fine. Scrub all over your hands and fingers—and don’t forget to scrub under your nails. Then use a clean towel to dry your hands.

You might want to buy some alcohol hand sanitizer to carry with you when you’re away from home. You can use these gels and lotions to clean your hands when there’s no water around.

What else can you do to prevent infection? Just be cautious and use common sense. Here are some examples:

- Do not touch your face with dirty hands.
- Avoid people who are sick, especially with the flu, measles, chicken pox, hepatitis, etc. If someone you
live with is sick, use common sense. For instance, don't share drinking glasses and utensils. Ask the sick person to always cough and sneeze into a tissue.

- Get adequate rest and proper nutrition so your body is better able to fight off infection.
- Wear gloves when working in the soil.
- Don't eat raw or undercooked meat, poultry, fish, or seafood.
- If you have a pet, ask a family member or friend to clean up the pet's waste. If you have to clean up animal waste, wash your hands thoroughly afterwards.

We recommend that you get flu and pneumonia shots. But check with your post-transplant nurse or doctor before getting your first flu shot after your transplant. We may ask you to wait one year after your transplant before getting the flu shot.

In fact, you should always check with us first before getting any type of vaccine or before anyone in your household has a "live virus" vaccine. Some vaccines, such as those for varicella (chickenpox), measles, smallpox, and polio, contain "live" viruses. A live vaccine can actually cause an infection for people who have a weakened immune system and can be transmitted from someone who recently had a vaccination.

If you suspect that you might have caught an infection, even a cold, it is a good idea to contact a post-transplant nurse. We would like to make sure that your transplanted organ function is
stable and that you get over the infection without a problem. Because of this, we recommend that you check your labs at least weekly for a couple of weeks after an illness to make sure things are stable. This is true for as long as you have your transplant.

Get Regular Health Exams and Screenings. After a transplant, it’s easy to forget about the rest of your body when you are so concerned about the health of your new organ. But remember, you need to keep your whole body healthy. So, be sure to schedule regular exams and screenings as needed. Often this is best done through your primary care doctor.

We recommend the following screenings:

- An annual Pap smear and breast examination, if you’re a woman.
- Regular mammograms if you are a woman over age 35.
- An annual eye exam to check for cataracts, glaucoma, and other eye diseases.
- Regular skin cancer exams by a doctor. If you have any unusual skin changes report these immediately. We recommend that you have regular visits with a dermatologist.
- An annual prostate exam, if you’re a man over age 45.
- Regular colorectal exams, if you are over age 50.

All transplant recipients should also pay attention to any unusual changes in their bodies or bodily functions (see Table
1, page 36). For instance, any changes in bowel or bladder habits or unintentional weight loss, should be reported.

You should also continue to visit any medical specialists whom you see for any conditions that are unrelated to your transplant, such as heart disease, asthma, or arthritis. It’s important that you keep any chronic health conditions under control. Patients with diabetes benefit from having a diabetes specialist (endocrinologist) manage their illness.

**Wear Your Medic Alert Identification Tag.** Because transplant patients require special care in emergency situations, it is important for you carry some form of identification to alert emergency medical personnel that you have a transplant. Medic alert jewelry is available from the National Kidney Foundation of Illinois and elsewhere. If you wish for more information, ask one of the post-transplant nurses.

**Take Precautions About Dental Care.** One of the reasons that we want you to see a dentist before your transplant is to prevent dental or gum problems following transplantation. After your transplant, check with us before you have any dental work done. To prevent infection, we may recommend taking an antibiotic before you get your teeth cleaned or have major dental work done. We follow the American Heart Association guidelines for prevention of infections with dental work.

**Commit to a Healthy Lifestyle.** If you’re good to your body, you may be less likely to have
complications or develop heart disease, diabetes, or another serious condition.

- **Eat a healthy, varied diet.** Some of the dietary restrictions you had prior to transplant may no longer be applicable. All transplant patients should consume a variety of foods, including lots of fruits and vegetables, so they get the nutrients they need to heal after surgery, stay strong, and fight off infection and disease. By minimizing your intake of sodium, fat, and calories, you can minimize post-transplant complications, such as weight gain, diabetes, and high blood pressure. Depending on your family history and lipid (cholesterol and triglyceride) levels, you may need to be especially careful about watching your fat intake to prevent or control heart disease and other health conditions. In addition, many transplant patients are given specific food instructions. For example, some transplant patients need to eat a low-sodium diet to control high blood pressure. Plus, patients who are taking cyclosporine or tacrolimus need to avoid grapefruit and grapefruit juice because it can alter how much of the drug is absorbed by your body. All of these dietary instructions can get confusing or overwhelming. Our transplant nutritionist is here to help you design a healthy eating plan that fits your lifestyle.

- **Exercise regularly.** Aim to get at least 30 minutes of moderate exercise on most days of the week. It can help prevent or control high blood pressure, heart disease, osteoporosis, and many other health
problems. Exercise can also help you lose weight or maintain a healthy weight. Plus, it's a great way to relieve stress and anxiety. Choose exercises that you like to do. Examples include brisk walking, swimming, biking, dancing, hiking, aerobics, or playing basketball. Housework and yard work also count toward exercise, if you get your arms and legs moving fast enough. Remember though, to start slow and avoid vigorous activity or weight lifting for the first four to six weeks after surgery. Please talk to one of the post-transplant team members if you are having trouble getting started on an exercise program or have other health conditions that make it difficult for you to exercise.

• **Maintain a healthy weight.** It's easy to gain weight after a transplant. If you were on dialysis before your surgery, you may find yourself overindulging in all the foods you have been denied. You may also notice an increased appetite after transplant. This may be because you feel better. Some medications might also stimulate your appetite. There is no secret to weight loss. You just need to eat less than you burn off through exercise and activity. Weight loss is not easy, but our transplant nutritionist can help you design an eating plan that can help.

• **Drink plenty of water, juice, or fluids.** Fluid is necessary for transplant function. If you don't take in enough fluids, you get dehydrated. So, aim to get 2.5 to 3 liters (80-100 ounces) of water or other
non-caffeinated fluids a day. Large amounts of fluid containing caffeine, such as coffee, cola, or tea, can dehydrate you, so you should limit these. Juices can contain a lot of sugar and potassium, so avoid these if you have problems with high blood sugar, weight gain, or high potassium levels.

• **Protect yourself in the sun.** To prevent skin cancer, practice safe sun habits. For instance, avoid going out in the sun in midday. When you are outside, stay in the shade when possible. Wear a sunscreen with a sun protection factor (SPF) of at least 30. A hat with a brim that covers the ears and nose is also helpful.

• **Get plenty of sleep and relaxation.** If you get rundown or overtired, your body will have a harder time healing and fighting off infection.

• **If you drink alcohol, do so in moderation.** Depending on your other health conditions, it is generally OK to have an occasional glass of wine or beer. But we would like you to wait to drink alcohol for four to six weeks after your transplant, once your medicines are at a stable level. If you have questions, ask the transplant doctor or nurse.

• **Avoid tobacco—even second-hand smoke.** Stopping tobacco use is one of the most useful things you can do to prolong your life. We are glad to provide help to stop if you are smoking or have returned to smoking. Just because you tried to quit and couldn’t doesn’t mean that you can’t be successful stopping
now. There may be medications that will help you quit. Another thing that is useful is to have everyone in the household quit smoking so that you are not around tobacco smoke at all.

- **Don't smoke marijuana or take other illegal drugs.** These drugs may interact with your anti-rejection medicines, lowering the levels in your blood and making them less effective at preventing rejection.

**How to Say Thank You**

After transplantation, many people look for helpful ways to express their gratitude for the health they now have. We offer several suggestions:

- Write an anonymous letter to your donor's family. If you'd like to do this, talk to one of the post-transplant nurses for more information.

- Volunteer as an educator at a dialysis unit. Contact the transplant social worker for more information. Some patients also volunteer with organizations that help promote organ donation, such as the National Kidney Foundation.

- Assist with fund-raising efforts for the University of Chicago Transplant Research Fund, including the annual golf tournament and banquet.
Common Questions About the Post-Transplant Period

Q. Will I be able to get pregnant and carry a child to term after the transplant?

A. Several thousand women have had successful pregnancies after transplantation, including several at the University of Chicago. There appears to be no increased rate of birth defects among children of transplant recipients. But the medicines that you take for rejection and preventing infection have not been well studied in regards to the effect on sperm, eggs, and the developing fetus.

Pregnancy following a transplant is not without risks. We recommend that you talk with your doctors before getting pregnant so you can make an informed decision. There is some risk of pregnancy affecting the function of a transplanted kidney and even a chance of rejection during or after pregnancy. Some patients do not want to take any chances with their transplanted organ function and choose to become parents through adoption.

In order to optimize the chances of a successful pregnancy and maintain transplanted organ function, we strongly recommend:

• Waiting until at least one year after transplantation and at least one year after any rejection episode before trying to become pregnant.

• Avoiding pregnancy unless your kidney function is excellent (creatinine less than 1.5).
• Have the transplant team consider adjusting medicines before becoming pregnant so that you are on the safest combination of anti-rejection medications for the fetus.

• Avoiding pregnancy if you have high blood pressure that is not well controlled.

A pregnancy in a transplant recipient requires you to be followed as a “high risk” pregnancy, preferably by both the obstetrician and the transplant team.

Both men and women are or become fertile soon after a successful transplant. Even women who have not had a period for a long time because they were on dialysis can get pregnant. So, we strongly advise the use of some method of effective birth control when you resume sexual relations.

**Q. How long will I have to take anti-rejection medicines?**

**A.** You will need to take anti-rejection medicines for the life of your transplant. It's vital that you never stop taking your anti-rejection medicines, or change the dose, unless your transplant doctor or nurse tells you to do so. Stopping your anti-rejection medications will eventually allow your body to reject the organ.

**Q. Will I gain a lot of weight after transplant?**

**A.** Patients gain weight after a transplant for several reasons:

• Some of the anti-rejection medicines may increase your appetite.

• Many patients were on restricted diets before their transplant. After the
transplant, they start overeating for the sheer joy of being able to eat or drink what they want.

• Your activity level is limited for a several weeks after your transplant surgery.

Keep an eye on what you eat. Try not to eat any more calories than you expend in exercise and daily activities. Get lots of exercise and fill up on fruits, vegetables, whole-grains, and other healthy foods. Avoid eating too many sweets or fatty foods.

If you are having trouble maintaining a healthy weight, ask our transplant nutritionist for help. Excess weight can raise your risk of heart disease, type 2 diabetes, and many other health problems.

Q. I had a transplant before and lost it to rejection, will this happen again?
A. We are performing more and more successful re-transplants every year. Your risk of rejection is higher than a patient who has never been transplanted before. Your immune system may be more “on the alert” for a foreign organ. To minimize the risk of rejection, we will put you on a “special” regimen of anti-rejection medicines designed just for you. With modern medicines, less than half of re-transplanted patients will experience acute rejection.

Q. Will my original kidney disease come back in the transplanted kidney?
A. It depends on the cause of your kidney disease. Very few kidney diseases actually come back in the transplanted kidney. We will watch you closely for
signs of recurrent disease, if applicable. Many problems that lead to kidney failure are from your own body attacking the kidney. Since the kidney that you receive is not exactly like the rest of you, the same kind of attack may not occur in the transplant. In addition, many of the same medications that you take to prevent rejection are commonly used to treat kidney diseases, such as glomerulonephritis.

Many transplant patients developed kidney disease as a result of diabetes. Will diabetes affect your new kidney? It takes a long time for diabetes to affect the kidney, usually more than 10 to 15 years. You can help prevent future disease in your new kidney by keeping your blood pressure and blood sugar under control.

Patients with type 1 diabetes might also consider getting a pancreas transplant, which can control their blood sugar without insulin injections. (Pancreas transplants generally do not help patients with type 2 diabetes. 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.)

Q. If I get a pancreas transplant, will type 1 diabetes affect that pancreas eventually?
A. In type 1 diabetes, the immune system attacks the insulin-producing cells in your pancreas. However, your immune system will probably not attack your transplanted
pancreas in that way (though rejection is a possibility). This may be because the transplanted pancreas “looks” different to your immune system than your own pancreas. Plus, anti-rejection medicines may protect the transplanted pancreas from an immune system attack.

### Table 1. When Should You Contact a Post-Transplant Nurse?

You will be seen frequently in the Post-Transplant Clinic so you will have ample opportunity to bring any questions or concerns that you may have. During clinic, you can request prescription refills, get documents completed (such as insurance forms or family leave forms), and ask any question that you might have.

If necessary, you can call and talk to a post-transplant nurse about a concern or problem outside of clinic hours. A voice mail system is provided and is checked frequently, and your call will be returned. A nurse is also available by pager 24 hours a day. This should be reserved for emergencies or to report serious changes in your condition, such as inability to urinate, fever greater than 100, vomiting which prevents you from keeping your medications down, or diarrhea that leads to dehydration. You should also call (or have someone call) if you are hospitalized unexpectedly. A nurse and transplant surgeon is available to talk with the doctors taking care of you at that time.
If You Experience Signs of Rejection

Most rejection episodes are now detected in lab tests before patients know anything is wrong. But it’s still important for you to know the signs and symptoms of possible rejection. If you experience any of these, contact us:

- An increase in temperature—call whenever your temperature is greater than 100 degrees Fahrenheit (38 degrees Celsius)
- A decrease in urine output
- An increase in blood pressure
- Swelling and/or tenderness over the site of your transplant
- Weight gain from less urine being formed—call if you gain more than 3-4 pounds at one time

If You Think You Have an Infection

Different infections have different symptoms. But signs may include:

- A fever of 100 degrees Fahrenheit or higher (38 degrees Celsius)
- Chills
- Diarrhea or vomiting
• Pus, swelling, redness, or odor around your surgical incision or a wound
• Joint and muscle aches
• Pain when you urinate
• A skin rash

If You Notice Any Unusual Changes

All transplant recipients should be alert to any unusual physical changes in their body or body functions, including:

• Blood in your urine or stools
• Unusual growths or moles on your skin
• Lumps or growths below your skin (for example, in a woman’s breasts or a man’s testicles)

If You Have a Medicine Question

Please contact us if you are unsure about how or when to take any of your medicines. You should also contact us before taking any medicines, supplements, or herbal products that were not prescribed by your transplant doctors. This includes over-the-counter medicines. Some medicines can damage your transplanted organ. We can let you know when you call us if a certain medicine is safe to take.

If You Are Hospitalized or Have a Medical Emergency

If you are ever admitted to any hospital, including the University of Chicago Hospitals, for any reason, you must notify us.
If you ever have to go to an emergency room, including the University of Chicago Hospital's emergency room, please tell the emergency staff to notify the Post-Transplant Clinic at the University of Chicago Hospital.

Transplant patients require special care, and our transplant doctors are available to consult with the doctors who will be treating you.

Table 2. Post-Transplant Clinic Location and Hours, Etc.

The Post-Transplant Clinic is located on the sixth floor of the Duchossois Center for Advanced Medicine (DCAM, 5758 S. Maryland Ave.) in Room 6A. The Blood Draw Lab is located down the hall in Room 6F.

Clinic Hours

The clinic is open on Mondays, Wednesdays, and Fridays. You need to arrive between 7:45 a.m and 10:15 a.m. No registration is accepted after 10:15 a.m.

Procedure for Post-Transplant Clinic Visits

1. Take the elevators in the DCAM building to the 6th floor. Go first to the Blood Draw Lab in Room 6F. Present any lab slips, and have your blood samples drawn.

2. Proceed to the Post-Transplant Clinic in Room 6A. Check in with the clinic clerk, then have a seat in the waiting area.
3. One of the clinic staff will call your name so you can be weighed and have your temperature and blood pressure checked. Afterwards, have a seat in the waiting area again.

4. When the results of your blood tests are completed, one of your transplant nurses will take you into an exam room.
You may be asked to keep track of some or all of these after your transplant.

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One Organ Recipient’s Post-Transplant Experience

*Debbie is a 42-year-old transplant patient who has received two kidney transplants and three pancreas transplants. Below she shares some of her post-transplant experiences.*

**On Clinic Visits**
The clinic visits provide a forum to visit and share your transplant journey with other recipients. Talking to other transplant patients can really help to alleviate your fears and anxieties. Many times we are able to find the humor that we experience, and it brings us together.

You really get to know the other patients because you see them at clinic so often, especially if you are transplanted about the same time. You’re going through the same number of clinic visits, three times a week. And then you all celebrate when you’re cut down to twice a week. You will go through these milestones together.

There’s such a nurturing, calm atmosphere at clinic. The three post-transplant nurses are all remarkable women. The wonderful thing about them is that they really take good care of your psyche and not just your body. Whenever I get worried or upset, they always calm me down and talk me through it. They're so amazing and dear. They really do care about each patient.

There are some times when clinic takes longer than the usual three or four hours, which can be upsetting. But never
in a million years can you skip a clinic. You can’t think, “Oh, I feel great, I’m not going to go to clinic today.” Because you can feel great and still have problems show up on your lab work. So it is vital that you do everything by the book. And never, ever be afraid to ask a question.

**On Biopsies**
You think of the word “biopsy” and become frightened or overwhelmed by the concept. I quickly learned that it is a simple procedure. I was so relieved after my first experience. Don’t be alarmed if you are told you need a biopsy. They are very common, especially during the first few months.

**On Medications**
In the beginning, the medications you need to take seem overwhelming. I think it is important that each patient come up with a system that works best for him or her. In the beginning, I would constantly read the labels and use the pill sheets with the pills taped on them. Then, I got this wonderful pillbox from the National Kidney Foundation of Illinois (Phone: 312-321-1500), which lets you organize your meds by the day of the week. Then, if you’re going out for the day, you can take out the pills for that one day and bring it with you.

I also always carry at least two days worth of medication in my purse. This way, if there is any circumstance that keeps me away from home, I have my meds. And there’s always a chance you might have to be hospitalized. So it’s always smart to bring your medications with you if you are admitted. Sometimes it can take a while for the hospital pharmacy to receive our orders.
On Medication Side Effects
All the immunosuppression has gotten so targeted, and every two years or so, there are new medications that cause fewer side effects and are less toxic to our organs. I've noticed a big reduction in the number and severity of side effects that transplant patients live with since I received my first transplant eight years ago.

The first three months after your transplant is the hardest in terms of side effects. Your doses of immunosuppressives are high then, including the steroid prednisone, so your emotions are very heightened. You feel like you are on a roller coaster. A teeny tear will turn into a half hour crying jag, and a giggle works into riotous laughter. It can feel strange. But as your doses are lowered, the side effects seem to disappear.

On Transplant Milestones
The three-month mark is a big milestone because your doses of immunosuppressants go down a little bit, and you can sometimes cut back on your number of clinic visits. And then at six months, it happens again. And, obviously the one-year mark is a big milestone. If you can get through one year without a rejection episode, it is really wonderful.

Every case is so unique. And you never know what might happen. I believe it is so important to be your own advocate and ask questions of the medical staff. We have been blessed by the gift of organs and MUST always treasure and respect them.