

Kidney Transplant Information for Recipients



Allina Health

Kidney Transplant Information for Recipients

Fifth edition

**Developed by Allina Health. This surgery is currently being performed at
Abbott Northwestern Hospital.**

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This publication is for general information only and is not intended to provide specific advice or recommendations for any individual. The information it contains cannot be used to diagnose medical conditions or prescribe treatment. The information provided is designed to support, not replace, the relationship that exists between a patient and his/her existing physician.

For specific information about your health condition, please contact your health care provider.





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Chapter 1: Introduction to Transplant and Evaluation

This booklet gives you basic information about a kidney transplant. You will be working closely with the members of your health care team to decide if a kidney transplant is right for you.

Your Transplant Team

You will work with a team of health care providers before, during and after your transplant.

- Transplant coordinator**
The transplant coordinator is a nurse who has received specialized training in kidney transplant evaluation and post-transplant care.
- Transplant surgeon**
The transplant surgeon will review the benefits and risk of the surgical process and will also be the doctor performing the transplant surgery.
- Nephrologist**
This is a doctor who specializes in treating people who have kidney disease and who have had transplants. The nephrologist will monitor transplant function and medications after transplant.
- Social worker**
The social worker will work with you and your family to help identify any needs you have, offer support, and give you information about resources in your community.
- Financial specialist**
The financial specialist will help you with your questions about insurance and billing. You are encouraged to call your insurance provider so you know your benefits.
- Dietitian**
The dietitian will answer your questions about what to expect with your post-transplant diet.
- Nurses**
They will provide inpatient care, education and support after the transplant.
- Pharmacist**
The pharmacist will answer your questions about medications. This includes prescription, over-the-counter, vitamins, herbal, and natural medications.

Transplant Coordinator

The transplant coordinator is your main contact with the transplant team. You will work closely with your coordinator during your evaluation and while you are waiting for a kidney. Please tell your coordinator if:

- your phone number(s) change
- your address changes
- you have changes in your medications
- you start dialysis, change dialysis centers or change your type of dialysis
- you have health changes (new problem or problem that gets worse)
- you are in the hospital or had a recent hospital stay
- you are scheduled for a surgery or procedure
- your insurance changes or you need to talk with the financial specialist
- you have questions about the transplant
- you had routine screens updated
- you will be out of town and how to contact you.

Good communication with your transplant coordinator is important to help make your evaluation go as smoothly as possible.

Your Role in the Evaluation and Transplant

You are an important member of your health care team and to the success of your evaluation and transplant. There are many things you can do to help make the evaluation process go smoothly:

- keep in close contact with your transplant coordinator during your evaluation
- stay up-to-date on routine screens and vaccinations
- update your coordinator with any changes.

While you are waiting on the transplant list:

- contact your coordinator with updates on your health status
- keep routine tests and vaccinations up to date
- report changes in your insurance or contact information to the financial supervisor or transplant social worker
- see your doctors as recommended
- go to dialysis as scheduled
- follow your diet and fluid restrictions as directed by your nephrologist
- do your best to stay healthy so you are ready when a kidney becomes available.

After transplant:

- Check and write down your blood pressure, weight, temperature and blood glucose (if needed) as directed.
- Go to all clinic appointments.
- Follow directions for how to take your medications.
- Have lab draws frequently.
- You will be encouraged to live a healthy lifestyle, such as eating well and exercising.



Chapter 2: Benefits and Risks of Kidney Transplant

Kidney Transplant Benefits

A kidney transplant offers several benefits compared to dialysis. Some of these benefits may include:

- improved quality of life
- a life free from dialysis
- feeling better and having more energy
- no dialysis diet or fluid restrictions
- more time to do what you enjoy
- an easier time while travelling
- a greater chance for a longer life.

Kidney Transplant Risks

As with any procedure and medications, kidney transplant has risks. The evaluation will help determine if kidney transplant is a safe option for you.

Surgery complications (problems)

Any surgery has risks, such as:

- reaction to anesthesia
- bleeding or clotting
- infection
- problems with the surgical site incision.

Delayed graft function

Your kidney may not work right away after surgery. This is called delayed graft function. The new kidney goes through a shock during the removal from the donor and transplant into you. While the kidney is recovering from the shock it may not work at all or only work a little.

The delay can last days to months after surgery. Most transplanted kidney will eventually make urine and work well.

If your kidney is not working, you may need dialysis, a biopsy or both. A biopsy is the best way for your doctors to know what is happening with the new kidney.

Rejection

Your body's natural response to anything that is not you is to try to fight it. If your body tries to fight off the new kidney, it is known as rejection.

Most cases of rejection happen in the first few months after the transplant but rejection can happen at any time, even years after the transplant.

There are two main types of rejection:

- **acute:** This rejection occurs quickly. Symptoms can include fever, flu-like symptoms, pain or tenderness over the surgery site, changes in your urine, or retaining fluids. Many people do not have symptoms.

Your lab results are usually the first sign that rejection is happening. If found early, acute rejection can often be treated successfully.

- **chronic:** This rejection occurs more slowly over time. Chronic rejection does not respond to medication changes like acute rejection. Symptoms of chronic rejection are similar to symptoms of kidney failure.

If your nephrologist thinks you are having a rejection, you may need a biopsy. A kidney biopsy is a test that can help your nephrologist know why your kidney is not working or not working well.

Infection

The anti-rejection medications you will take to protect your new kidney will lower your body's ability to fight infections. Your greatest risk for infection is the first 6 months after your transplant or after being treated for rejection. This is the time your anti-rejection medications are at their highest doses.

There are many types of infections. After transplant, you will take medications to help prevent some common infections.

The transplant coordinator will teach you about:

- post-transplant infections
- medications used to prevent and treat infection
- monitoring signs and symptoms of infection
- what to do if you think you have an infection.

Signs of infection after a transplant include:

- fever higher than 100.4 F
- feeling like you have the flu (chills, aches, cough)
- nausea, vomiting, diarrhea
- sore throat
- pain or burning when you urinate
- feeling like you have to urinate often
- a wound that does not heal, is red, is warm to the touch, has drainage
- fatigue or feeling worn out
- muscle or body aches.

Cancer

Your risk of cancer after kidney transplant is increased because your immune system is unable to work as well as it should due to the anti-rejection medications.

You will receive education on how to lower your cancer risk and how to identify potential problems early. Some tips include:

- Use sunscreen and try to decrease the amount of time you are exposed to the sun.
- Get routine screens for cancer (such as mammogram, Pap or pelvic exam, prostate exam or colonoscopy).
- Get yearly dermatology (skin) checkups.
- Talk with your doctor about any changes in moles or your skin.
- Tell your doctor if you have any new or unusual symptoms.

Collection of lymph fluid (lymphocele)

A lymphocele is a collection of lymph fluid near your new kidney. It usually occurs within the first few months after transplant surgery.

If the lymphocele is small, your body will usually reabsorb the fluid and you won't need treatment. If it is large, presses on the kidney, causes pain or leaks from the incision, you may need a procedure to drain the fluid.

If a drainage tube is needed, it will be taken out when the drainage stops.

Clotting problems (deep vein thrombosis)

Blood clots can form in the deep veins in your legs after surgery. This is known as deep vein thrombosis (DVT). The clots form when you cannot exercise or be active. Symptoms are swelling, tenderness and warmth of the affected area.

To help prevent clots, you will:

- be encouraged to walk soon after surgery
- wear special wraps on your legs that will keep your blood moving
- receive heparin (a medication to keep your blood from clotting).

High blood pressure (hypertension)

High blood pressure (hypertension) is a common problem. Underlying high blood pressure may or may not improve with a kidney transplant.

You will need to check your blood pressure at home and bring your blood pressure log to your clinic visits. If your blood pressure is too high, it may cause damage to your new kidney. You may need to take medications or have doses adjusted to lower your blood pressure.

High blood glucose (hyperglycemia)

Some of the medications used in transplant can cause high blood glucose levels. This can happen if you do or do not have diabetes. There is a chance that if you did not have diabetes before surgery you could have it after surgery.

If your glucose level stays high, you may need to start a medication to lower it. If you have diabetes, your medication dose may need to be changed.

High blood fats (hyperlipidemia)

Hyperlipidemia is an increase in the amount of cholesterol and triglycerides (fats) in your blood. When the levels are too high, they can lead to heart disease and other problems.

There are no symptoms. The only way your doctor can tell if you have high levels is by doing a blood test. The test will measure your total cholesterol, HDL (“good”) cholesterol, LDL (“bad”) cholesterol and triglycerides.

You can manage the amount of fats in your blood by maintaining a healthy weight, getting regular exercise and taking medications as directed.

Kidney disease

Some types of kidney diseases can return after a transplant.

Some problems such as high blood pressure and diabetes can affect your new kidney even if they didn’t cause your native kidneys to fail. Good control of blood pressure and diabetes is important to your new kidney and overall health.

Death

Death is rare. Most people do well during and after transplant surgery but, once in a while, a serious complication can happen. You will have many tests to make sure that you are a candidate for a transplant and that your risk for serious complications is low.



Chapter 3: How to Tell if You are a Transplant Candidate

Evaluation

You will have several tests and routine screens to help the transplant team determine if you are a candidate for a transplant. Tests are based on your age, gender and health history.

Some tests will be at Abbott Northwestern Hospital. Others (like routine screens) will need to be scheduled with your primary care provider. Your coordinator will help you know which tests are needed and where to do each one.

You are possibly a candidate for a transplant if you:

- have end-stage kidney disease (you need dialysis) or you have chronic kidney disease (a creatinine clearance of less than or equal to 20) but not yet on dialysis
- you have 2 years or longer to live
- you are at least 18 years old.

If you are age 75 or older, your transplant coordinator will talk with you about more criteria.

While kidney transplant has many potential benefits for most people, for some people, the risks outweigh the benefits. You might not be a candidate for a transplant if you:

- currently have an infection (even if it is being treated)
- have cancer or have not been cancer-free for long enough
- are a high-risk for anesthesia
- have many other health problems that may make surgery and/or recovery difficult or dangerous
- are dependent on drugs or alcohol
- are not following your current treatment plan (non-compliant)
- unable to follow complex medical regimen required after transplant
- have a body mass index of 35 or higher
- have unstable psychiatric illness
- have inadequate social support system
- have inadequate insurance/financial resources to cover expected post transplant expenses.

Screens

The tests you need are based on your age, gender and health history. Follow the checklist you received from your transplant coordinator. Examples of screening tests are:

- mammogram (women age 40 and older)
- Pap smear and pelvic exam (women, based on primary care provider's recommendation)
- PSA (men age 50 and older)
- colonoscopy (men and women age 50 and older)
- dental exam and clearance (men and women, all ages)
- Mantoux skin test (for tuberculosis): every 2 years.

The above are general guidelines. Your recommendations may be different. Your coordinator will tell you what tests you need.

Vaccinations

You will also need to update your vaccinations to help lower your risk of getting some infections. Examples are:

- flu shot: every year
- Pneumovax®: due every 5 years
- Prevnar®: one time dose
- tetanus/diphtheria/pertussis (Tdap): every 10 years
- hepatitis B series: usually only needed once
- Shingrix®: series of 2 injections
- additional vaccinations as recommended.

Talk with your coordinator if you have questions.

Specific testing for transplant

In addition to the screens and vaccinations, you will need some specific tests for transplant. You will be scheduled for these tests at Abbott Northwestern Hospital.

Examples of tests you may need are:

- heart stress test or echocardiogram
- chest X-ray
- chest CT
- CT abdomen and pelvis
- labs that are specific to transplant (see below for additional information)
- surgical consult
- dietitian consult
- social worker consult.

Lab work

There are many lab tests you will need that are specific and unique to transplant. These tests help determine DNA and compatible donors as well as other important information for transplant.

Blood type

This is the first test to determine if a donor is potentially compatible with you. You don't always need to be the same blood type as a donor but you do need to be compatible. The Rh factor (+ or -) does not matter for a kidney transplant.

(ABO Compatibility)	
Your blood type	Blood types from which you can accept a kidney
O	O
A	A or O
B	B or O
AB	A, B, AB or O

Tissue typing

This blood test determines your genetic markers called antigens. Your body knows your own antigens as you, or self. Your body sees the donor antigens as foreign or non-self.

Your body's natural response is to fight off those non-self antigens. This is called rejection.

Each person has many antigens but there are 6 key antigens for transplant. Each recipient and potential donor will have their own antigens checked as part of the evaluation. This helps to determine if a potential donor is compatible with the recipient.

Antibody levels

Antibodies are part of your immune system that can develop after exposure to someone else's DNA. If you had a blood transfusion, a previous transplant or been pregnant, you may have developed antibodies.

Antibodies watch for repeated exposure to foreign DNA and attack quickly if encountered.

If you have antibodies to your donor's antigens, you may not be able to receive a kidney from that donor. If you have antibodies, your transplant coordinator will provide more information and how it may impact transplant for you.

Crossmatch

This blood test combines your blood with blood from a potential donor to see if your blood reacts to the donor blood.

- If your blood does not react to the donor's blood, the test is negative. This means you can receive the donor's kidney.
- If your blood does react to the donor's blood, is positive. This means you cannot receive the donor's kidney.

Summary

Once your tests are done, your transplant coordinator will review the results with your transplant team. If all testing is done and transplant is a safe option for you, you will be added to the deceased donor waiting list, even if you have potential living donor(s).

If you have a living donor who is already approved, surgery may be scheduled.

If additional testing is needed or there are concerns that transplant is not a safe option for you, your coordinator will discuss this with you.

If at any time during your evaluation you have questions, contact your transplant coordinator.



Chapter 4: Types of Donors

Living Donors

A living donor can be any person who willingly comes forward to be evaluated for possible donation. This may be a family member, friend, or other person you know. Occasionally people get a kidney from a donor they do not know after posting on social media or getting their story out.

The potential donor will have many tests and consults to be sure they are healthy enough to donate a kidney and that donation is a safe option for them.

- In the United States, it is illegal to buy or sell kidneys. Donors must come forward willingly without financial compensation.
- Benefits of receiving a kidney from a living donor include:
 - shorter time waiting for transplant
 - the kidney usually works right away
 - the kidney usually works longer than a kidney from a deceased donor
 - ability to plan surgery
 - you may be able to avoid starting dialysis if you have not yet started.

Deceased Donors (Waiting List)

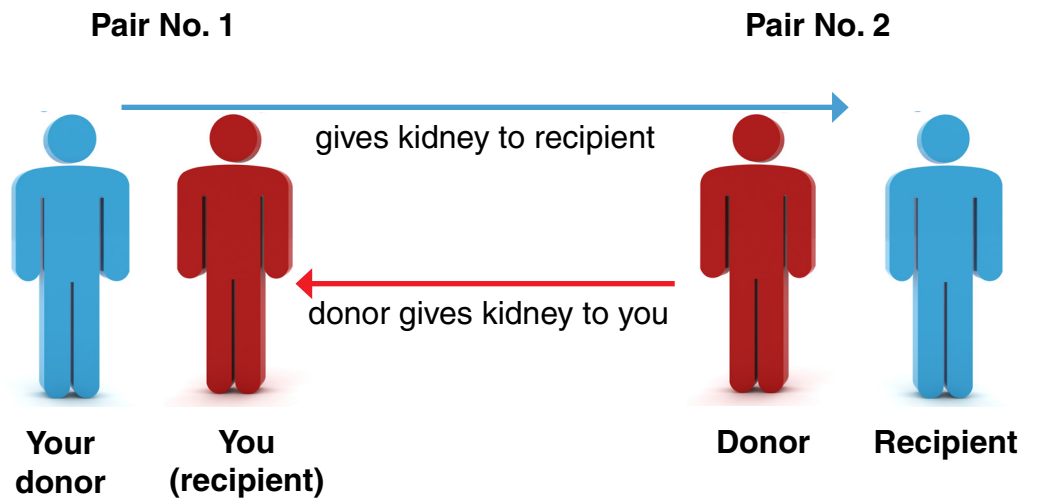
- Once you are approved as a candidate, your name will be placed on a nationwide waiting list for a kidney from a person who has recently died.
 - The average waiting time for this type of donor is 5 to 8 years.
- When a kidney is offered from a deceased donor, a transplant coordinator and surgeon will review the donor information and your current status to determine if the kidney is appropriate to transplant. If the surgeon thinks it is a good offer, a coordinator will call you any time during the day or night to discuss and give you instructions.
- It may take time for the kidney to work after transplant; this is called delayed graft function. Delayed graft function is more common with kidneys from deceased donors. During this time, you may need dialysis until the kidney is working better.

Paired Exchange Program

If you have a living donor who is not compatible with you, you and your donor can enroll in the Paired Exchange Program.

This program tries to find matches among people whose donors don't match them but might match someone else who has a living donor. If there's a match, your donor would donate to the other recipient and that person's donor would donate to you.

Your transplant coordinator can give you more information.



Chapter 5: Transplant Surgery

Living Donor

Once you and your donor have completed the evaluation and it has been determined that transplant is a safe option for both, surgery is scheduled for a time that works best for you and your donor.

About 1 week before surgery, you and your donor will be scheduled for a pre-surgery visit at Abbott Northwestern Hospital. At this visit, you will:

- have blood drawn
- have a chest X-ray
- have an EKG
- see the surgeon
- have a history and physical exam
- receive directions to prepare for surgery (including arrival time to hospital, what medications to take before surgery, and when to stop eating and drinking before surgery).

Deceased Donor

You will need to have all of the tests listed above but you will not be able to plan a pre-surgery visit because it is not known ahead of time when a donor will become available.

When a kidney is available from the waiting list, a transplant coordinator will call you with instructions. This call could come at any time of the day or night.

If the transplant coordinator cannot reach you within 1 hour, the kidney offer may have to be declined for you. These rules are set by United Network for Organ Sharing (UNOS) in order to make the best use of available kidneys. Abbott Northwestern Hospital staff cannot adjust these rules.

To make sure the transplant coordinator can reach you at any time:

- Give your coordinator your current phone numbers.
(This includes the people you have on your contacts list.)
- Have your phone with you at all times.
- Make sure your cell phone is charged.
- Don't put your cell phone on silent or vibrate modes at night.

- Make sure to tell family and friends if you have listed them as alternative contacts. They need to know to answer their phone day or night.
- If you do not recognize a number on caller ID, please answer the phone; it may be a coordinator calling.
- If a coordinator leaves you a message, follow instructions to promptly return call.

Transplant Surgery

Before surgery

- When you come in for surgery, you will be brought to the Pre-operative Care Center to prepare.
- If you are receiving a deceased donor kidney, you may be admitted to a room while final preparations are being made. Since each case is different, a coordinator will give you instructions for your situation.
- You will meet the members of your surgery team, meet with the surgeon and meet with the coordinator. You will have a chance to ask them questions before surgery.
- When you are ready for surgery, you will be given general anesthesia to put you to sleep.
- You will have a breathing tube inserted through your mouth to help you breathe while under anesthesia.
- You will have a Foley catheter in your bladder to collect urine. The catheter will stay in place for 3 to 4 days after surgery.
- The surgery team will clean and prep your lower abdomen for surgery in preparation for the transplant.

During surgery

- An incision will be made into your lower abdomen. The incision will be about 6 to 8 inches long.
- The kidney will be placed in your lower abdomen on either the right or left side.
- The surgeon will use blood vessels in your legs to supply blood flow to the transplanted kidney.
- The ureter will be connected to the bladder.
- A stent (small flexible tube) will be inserted into the ureter to help allow for healing in this area. The stent will be taken out about 3 to 6 weeks after surgery.

- Once the new kidney is in place, the surgeon will close the incision.
- You will go to the recovery room where you will wake up from the anesthesia.
- In the recovery room, you will have an ultrasound of the transplanted kidney to check blood flow.
- Your surgeon will give your family or friends an update.
- After your time in the recovery room, you will go to a floor where nurses are trained to take care of people who had transplant surgery.
- Once you are settled into your room, your family and friends can visit you.

You may need a short stay in the Intensive Care Unit before going to your room. This is rare and is usually for a short time.

After surgery (in the hospital)

- You may feel tired. This is your body's response to the anesthesia.
- You will have some pain at the incision site. You will have pain medication to help decrease pain.
- Your nurse will help you sit up in a chair and walk. You will be encouraged to walk soon after surgery and often to help with recovery.
- Your nurse will show you how to cough and deep breathe.
- You will wear special compression stockings on your legs to help prevent blood clots.
- You will have 1 or 2 intravenous (IV) lines in your hand or arm to receive medications and fluids.
- Your health care team will check your bladder catheter to see how much urine you are making. This helps the doctors and nurses know how well your kidney is working.
- You will be connected to a heart monitor to watch for any changes in your heart rate or rhythm.
- A transplant coordinator will see you every day to provide education.
 - They will teach you about your medications, possible problems, how to take care of yourself at home, planning for discharge from the hospital, and clinic follow-up.

After surgery (at home)

At discharge, you will receive specific self-care directions. In general:

- Do not drive until you are done taking prescription pain medication and your incision has healed.
- Do not lift more than 10 pounds for about 6 weeks after surgery. Lifting restrictions will be talked about in the post-transplant clinic.
- Travel is not recommended in the first several months.
- Keep all clinic and lab appointments.
- Take your medications as directed.
- Follow directions for watching for signs and symptoms of problems and for home monitoring.
- Stop doing any activity that causes pain.

Know whom to call and when to call for any questions or concerns.

Chapter 6: Transplant Medication

General Information

Your body's natural response is to fight off your new kidney. This is called rejection. To try to keep your body from rejecting your new kidney, you need to take anti-rejection medications, also called immunosuppression, for as long as your kidney is working.

Your coordinator and nurses will start to teach you about your medications while you are in the hospital. You will continue to learn about your medications at post-transplant clinic appointments.

If you have any questions about your medications, ask a transplant coordinator, nephrologist or surgeon.

When you are ready to go home, a coordinator will help you set up your medications in a pill box until your first clinic appointment.

The nurses at the Transplant Clinic will help you with your medications until you can set them on your own. A family member or friend can learn and help you at home.

Important

- Always check with your nephrologist *before* you take any other medications. This includes prescriptions from other doctors, over-the-counter products, vitamins, natural products or traditional medications or remedies.

Some medications cannot be taken with your transplant medications. Taking them could harm the transplanted kidney.

- Do not change any of your medications on your own. If you think you are having side effects from a medication, call the Transplant Clinic.

Transplant Medications and Possible Side Effects

You will take a combination of anti-rejection medications.

Some of these are given to you through your IV right after surgery and some are pills you will continue to take once you go home.

Most medications have side effects. Some common side effects are listed under each medication.

❑ **Prednisone**

- Prednisone is a steroid that is used as an anti-rejection medication.
- You will receive the first 2 doses through your IV line. After that, you will then receive your dose in a pill.
- Your coordinator or doctor will tell you how long you need to take prednisone. If you are taking it for a long time, you will follow a taper schedule. A coordinator will explain your taper to you.
- Possible side effects are:
 - increased appetite and weight gain
 - indigestion
 - mood swings
 - increased blood pressure, cholesterol and glucose
 - swelling of the face, feet or ankles.

❑ **Tacrolimus (Envarsus® or Prograf®)**

- Tacrolimus is an anti-rejection medication.
- Tacrolimus will be started while you are in the hospital.
- You will have levels checked to make sure the dose is right.
- Possible side effects are:
 - nausea or vomiting
 - tremors (shaking)
 - hair loss
 - high blood pressure
 - increased blood glucose levels.

- Mycophenolate mofetil (Cellcept® or Myfortic®)**
 - Mycophenolate is an anti-rejection medication.
 - Mycophenolate will be started while you are in the hospital.
 - Possible side effects are:
 - low white blood cell count and hemoglobin
 - nausea, vomiting and diarrhea.
- Thymoglobulin**
 - Thymoglobulin is an anti-rejection medication. You will receive 4 or 5 doses through your IV line.
 - Possible side effects are:
 - flu-like symptoms
 - low white blood cell count and platelet count
 - allergic reaction.
- Basilixumab (Simulect®)**
 - Basilixumab is an anti-rejection medication. You will receive 2 doses through your IV line.
 - There are usually no side effects.

Preventive Medications

You will take several preventive medications after transplant. You will take these medications for 2 to 6 months. You may take all or some of the these:

- antibiotic to help prevent some common infections caused by bacteria
- antifungal to help prevent a common infection caused by fungi (yeast)
- antiviral to help protect against a common infection caused by a virus
- medication to help decrease stomach acid and prevent ulcers
- medications to help prevent constipation.

Other Medications

You may need to take medications for other health issues. For example, you may need to take medication to control your blood pressure, cholesterol or blood glucose.

A kidney transplant doesn't cure those health issues so you will need to take medications to control them.



Chapter 7: Transplant Clinic Follow-up Appointments and Labs

Preparing for Transplant Clinic

When you are ready to go home from the hospital after transplant surgery, a transplant coordinator will give you information about your first follow-up clinic appointment.

At your first follow-up visit, the Transplant Clinic nurses will give you directions about future clinic visits. In general, you can expect to go to the clinic 3 times a week for the first several weeks after the transplant. Your schedule may change based on your needs.

All follow-up visits and lab checks are important. Please keep all appointments, even if you are feeling well. If your body is rejecting the kidney, the first sign will likely be found in your lab results. By the time you are not feeling well, the rejection could be severe and difficult to treat.

Time After Transplant	Number of Clinic Visits, Lab Draws or Both
discharge to 4 weeks	2 to 3 times a week
4 to 12 weeks	1 to 2 times a week
3 to 6 months	1 time a week to 1 time every 2 weeks
6 to 12 months	1 time a month
1 to 2 years	every 2 months
more than 2 years	every 3 months

In time, your clinic appointments will be more spread out and less often. It's important to follow your lab schedule. Call your transplant coordinator if you are unsure if you need labs.



Chapter 8: Lifestyle Considerations After Surgery

Guidelines

You will receive information about what you can and cannot do after surgery. The following is general information.

❑ Activity

- Follow your lifting restrictions.
- Walk as much as you can.
- Increase your physical activity as you are able.
- If you are not used to exercise, talk with your primary care provider about how to safely start once your nephrologist says it is OK to start.

❑ Returning to work

- You should be able to return to work 6 to 8 weeks after surgery. This depends on what you do, how your recovery is going and what your employer expects.
- If you have problems after surgery, your return to work may be delayed.
- If you received disability benefits because of kidney failure, you may no longer qualify for disability after transplant. If you have questions about this, talk with your social worker *before* transplant surgery.

❑ Diet

- You will see a dietitian before you get discharged from the hospital.
- Once your kidney is working, your diet needs will change. A transplant coordinator will talk to you about your needs at your clinic appointment.
- If you need to follow another type of diet (such as for diabetes or heart health), you will still need to follow those guidelines.

❑ Travel

- Do not travel for the first few months after surgery.
- Always keep extra doses of your medications with you when you travel in case you are delayed or miss a plane, train or bus.
- Keep a current medication list with you.
- Have your pharmacy phone number with you.
- **Always** pack your medications in your carry-on case when you fly.
- Wash your hands often or use hand sanitizing gel to avoid infections.
- If you are traveling overseas, additional precautions may be needed.

❑ Sexual activity

- After surgery, you should have more energy and feel better. You can continue sexual activity when your incision is healed and you feel comfortable.
- **Women:** If you are planning a pregnancy after a transplant, talk with your nephrologist first. Some of your transplant medications can cause harm to an unborn child.
- **Men:** Talk with your nephrologist before you father a child.

❑ Family relationships

- Kidney failure and transplant can put stress on your family.
- Talk with your social worker if you or any family member want to learn about resources that can help with this stress.

Chapter 9: Financial Considerations and Insurance

Insurance

It is important for you to check your insurance benefits before transplant. If you do not understand your benefits, call your insurance company. See worksheet at the back of this booklet for questions to ask and how to document your call(s).

- Ask your insurance provider:
 - exactly what your policy covers
 - what your copays, deductibles, and out-of-pocket expenses will be
 - if you need to get referrals from your primary care provider
 - if and when you need to call your insurance company (such as when you enter the hospital for surgery).
- Your social worker or financial specialist can help you work with your insurance provider.

Important

If your insurance changes, you need to call your transplant coordinator. Insurance companies and policies have different benefits at different hospitals.

If your insurance changes, you might not have transplant benefits at Abbott Northwestern. It is important to know this before you receive a kidney transplant. Any expenses not covered by insurance is the patient's responsibility per insurance policies.

Medicare

If you have end stage renal disease, Medicare will pay for kidney transplant and dialysis. You are eligible for Medicare regardless of your age if you need a transplant or dialysis.

To qualify for Medicare Part A (hospital insurance):

- you or your spouse must have worked the required amount of time under Social Security, the Railroad Retirement Board or as a government employee.
- you, your spouse or a dependent child are receiving or are eligible for Social Security or Railroad Retirement case benefits.

You may also enroll in Medicare Part B (medical insurance). For this, you pay a monthly fee, or premium. Most of the services and supplies needed by people who have end stage renal disease are covered under Part B.

Both Medicare parts A and B cover kidney transplants as long as they are done in transplant centers approved by Medicare.

If you also have private insurance, Medicare will be your secondary carrier during the 30-month coordination period. This means your private insurance will pay for most of the bills during this period.

To enroll in Medicare

You can enroll in Medicare at your local Social Security office. For the office nearest you, call 1-800-772-1213 from a touch tone phone. You will be asked to punch in your zip code and leave a recorded message. Your social worker can help you if you have questions.

Costs

Transplant costs fall into 1 of 3 areas:

■ Evaluation

- This includes routine screens and vaccinations. These can be done with your primary care provider. Your insurance will be billed since they are part of wellness checks.
- This also includes special tests for transplant evaluation. These are done at Abbott Northwestern. Your insurance will be billed for these at the time of transplant.

■ Surgery

This includes your hospital stay for the transplant and fees from your health care team.

■ After care

This includes follow-up care and long-term medications.

If you have questions about your coverage, call your insurance provider, social worker or financial specialist.

Keeping Track of Information

What to do when calling your insurance provider, Medicare, Social Security office or any health care provider

Anytime you call your insurance provider, Medicare, Social Security office or any health care provider, do the following.

- Write down the date and time of your call.
- Write down the first and last name and title of the person with whom you spoke.
- Write down a summary of your call. If someone says something you do not understand, ask to have the information repeated or said more clearly.

How to keep track of your materials

You may be overwhelmed by the amount of information you receive as you go through the transplant process. To help you stay organized, you may want to keep your papers in files and use notebooks with pockets.

- Keep all Explanation of Benefits (EOBs) from any of your insurance providers.
- File all health care bills by provider. You may have one for dialysis, one for your primary care provider and one for the hospital.
- Keep your files organized by date.
- Sign up for Allina Health account to make appointments, send medical messages, check your lab results, and more. See page 47.



Chapter 10: Resources

Websites

Show information you find on the internet to a transplant coordinator to make sure it is medically correct. Reliable websites to visit include:

- Allina Health: allinahealth.org
- National Kidney Foundation: kidney.org
- Life Options: lifeoptions.org
- United Network for Organ Sharing: unos.org
- The Transplant Patient Partnering Program: tppp.net.

Quit Tobacco For Your Surgery

Did You Know?

Tobacco products contain more than 7,000 chemicals. More than 70 are known to cause cancer.

Tobacco and surgery risks

Tobacco products include cigarettes, electronic nicotine delivery systems (ENDS, includes e-cigarettes), cigars, smokeless tobacco (dip or chew), hookahs, pipes, roll-your-own, and oral and oral nicotine products.

Using tobacco increases your risk of the following during and after surgery:

- heart problems
- lung problems (complications) such as pneumonia
- infections such as infections of your surgery site (incision)
- blood clots
- slower healing of your surgery site
- higher levels of pain and more problems with pain control.

Tobacco use keeps oxygen from reaching your surgery site and it can increase your recovery time.

Benefits of quitting

- Research shows that quitting 4 weeks before surgery can reduce any problems after surgery up to 30 percent.
- People who quit smoking report having better pain control.
- Your body responds quickly to quitting:
 - **8 hours:** the carbon monoxide level in your blood drops to normal. The oxygen level in your blood increases to normal.
 - **48 hours:** Nerve endings start to grow again.
 - **2 weeks:** Your circulation improves and your lung function increases. (Source: World Health Organization)

When you should quit

Ideally, you should quit as soon as possible. Research shows that:

- the harmful effects from cigarettes begin to go down about 12 hours after your last cigarette smoked
- at least 8 weeks without cigarettes is the best way to reduce problems almost as low as people who do not smoke.

The American College of Surgeons recommends at least 4 weeks without cigarettes.

You should not use tobacco the day of surgery up to 1 week after your surgery. Your doctor may tell you when to quit before your surgery.

If you quit for surgery, you double the chance of staying off cigarettes for good. Many people report they have no cravings while in the hospital.

Did You Know?

Using your surgery as a motivator to quit tobacco increases your success rate of quitting for good.

Nicotine Replacement Therapy (NRT)

NRT can nearly double your chances of successfully staying off cigarettes. It works best if you use it with the help of a doctor or counselor.

Ask your doctor about using NRT around the time of surgery.

Go to quitforsurgery.com to learn more.

Not ready to quit? Consider taking a break!

If quitting tobacco makes you feel nervous and seems overwhelming, consider taking a break or a vacation from tobacco use.

- You will get the physical benefits for the period of time that you are not using tobacco.
- You will reduce your risk of problems during surgery and still increase your chances of a smooth recovery after surgery.

If you can, set a goal to stop using tobacco for 1 month after your surgery. This will allow your body to heal the best after your surgery.

Ways to quit or take a break

- abrupt stop (cold turkey)
- nicotine replacement therapy* (gum, lozenge, patch or inhaler)
- medicines (varenicline and Zyban®)
- behavioral strategies (such as calling a friend or going for a walk)
- aromatherapy (black pepper oil)
- take a break (vacation) from tobacco.

Any step you take without tobacco is going to help you. Small steps are better than nothing!



Product-specific Resources

- financial aid Nicotrol® inhaler
 - 1-844-989-PATH (7284)
 - pfizerrxpathways.com
- Plant Extracts aromatherapy
 - 1-877-999-4236
 - plantextractsinc.com

Resources

Allina Health (for your hospital stay)

- Tobacco Intervention Program at Abbott Northwestern Hospital
 - 612-863-1648
- Tobacco Intervention Program at Mercy Hospital
 - 763-236-8008
- Tobacco Intervention Program at River Falls Area Hospital
 - 715-307-6075
- Tobacco Intervention Services at Allina Health United Hospital – Hastings Regina Campus
 - 715-307-6075
- *United Hospital Lung and Sleep Clinic Tobacco Cessation Program
 - 651-726-6200
- *Penny George™ Institute for Health and Healing (LiveWell Center) tobacco intervention coaching
 - 612-863-5178

Other

- Quit Partner
 - 1-800-QUIT-NOW (1-800-784-8669) or quitpartnermn.com
 - American Indian: 1-833-9AI-QUIT or aiquit.com
 - Spanish: 1-855-DEJELO-YA (1-855-335-3569) or quitpartnermn.com/es
 - asiansmokersquitline.org
- online tobacco cessation support
 - smokefree.gov
- American Lung Association/Tobacco Quit Line
 - 651-227-8014 or 1-800-586-4872
- *Mayo Clinic Nicotine Dependence Center's Residential Treatment Program
 - 1-800-344-5984 or 1-507-266-1930

***There may be a cost to you. Check with your insurance provider.**

Glossary

ABO blood typing: Blood typing is done to see if a donor and recipient are compatible. A donor and recipient do not always have to be the same blood type but they must be compatible. Blood types include A, B, O and AB. The Rh factor (+ or -) does not matter.

Antibiotic: A medication used to fight infection from bacteria.

Antibodies: Proteins made by your immune system to fight off things that are not you.

Biopsy: A procedure to remove a sample of tissue, cells or fluid.

Cholesterol: A type of fat that is found in foods from animals. A diet high in cholesterol can cause health problems.

Clots: A clump of blood cells that interfere with blood flow.

Crossmatch: Blood tests to see if a donor's kidney is compatible with you.

Cytomegalovirus (CMV): A type of virus that can cause an infection which can be serious after transplant.

Deceased donor: A person who has died and consent was given to donate organs.

Delayed graft function: A kidney may not work right away after surgery. This is more common with deceased donor kidneys but it can happen with living donor kidneys. The delay can last days to many weeks. Dialysis may be needed until the kidney starts to work.

Diabetes: A disease that keeps your body from using glucose like it should. Your body has trouble moving the glucose from your blood into your cells causing the level of glucose to rise in your blood.

End-stage renal disease: This is permanent kidney failure. You need dialysis or a transplant.

Foley catheter: A tube is placed into your bladder to drain urine.

Glucose: A type of sugar in the body.

Hypertension: Another name for high blood pressure.

Immunosuppressants: These are medications that suppress your body's natural response to anything foreign or non-self.

Living donor: A person who offers a kidney for a transplant.

Recipient: A person whose kidney no longer works and has had a transplant.

Rejection: This is your body's natural response of fighting off a foreign object, such as a transplanted kidney. The rejection can occur quickly (acute) or more slowly over a long period of time (chronic).

Renal: Having to do with the kidneys.

Steroid: A medication used to treat many health issues. It is used after transplant for immunosuppression.

Tissue typing/HLA typing: This is a blood test that looks at the genetic markers of donors and recipients. The markers are compared to see how many the donor and recipient have in common. The best match is six out of six but you don't need to match any to have a successful transplant.

Transplant: A surgery done to replace a failed kidney with a healthy kidney.

Questions for My Insurance Provider

1. Is the transplant a covered service under my policy? Yes / No

2. What is my lifetime maximum amount or cap? _____

Cap amounts may apply to: one procedure / treatment or illness
all procedures / treatments or illnesses combined

3. Is there a pre-existing clause? Yes / No

4. What are my outpatient coverage benefits? _____

5. What are my benefits for medicine or prescription coverage? _____

6. Is a second opinion required (two doctors or two transplant hospitals)? Yes / No

7. Are there any deductibles or copayments? Yes / No

8. Are there separate deductibles or copayments on prescriptions? Yes / No

9. Is there a provider network or center of excellence for the type of transplant I need? Yes / No

There are policies that will not provide benefits for transplants that are not performed at a designated provider or center of excellence. Some policies provide benefits for the patient's transplant at non-designated centers but the out-of-pocket costs (yours) are higher. Other negotiated benefits apply at the center of excellence as well.

10. Do I need authorization before I can have surgery? Yes / No

Other questions or information: _____



Learn more about the Allina Health account



Easy appointment scheduling
In-person and virtual visits,
appointment reminders and updates



Care for the whole family
Gain access to another person's
account (proxy access)



Virtual care options
On-demand urgent care and
scheduled virtual visits



Prescriptions and billing
Manage payments, order refills and
track prescriptions



Info all in one place
Health records, lab results and
appointment notes



**Communicate with your
care team**
Send and review messages

Make health care easier with an online, all-in-one way to manage care.

Get started at
AllinaHealth.org/account



Nondiscrimination in Health Programs and Activities

Affordable Care Act – Section 1557

Allina Health complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, gender identity or sex. Allina Health does not exclude people or treat them differently because of race, color, national origin, age, disability, gender identity or sex.

Allina Health:

- provides free aids and services to people with disabilities to communicate effectively with us, such as:
 - ◊ qualified sign language interpreters, and
 - ◊ written information in other formats (large print, audio, accessible electronic formats, other formats)
- provides free language services to people whose primary language is not English, such as:
 - ◊ qualified interpreters, and
 - ◊ information written in other languages.

If you need these services, ask a member of your care team.

If you believe that Allina Health has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, gender identity or sex, you can file a grievance with:

Allina Health Grievance Coordinator
P.O. Box 43
Minneapolis, MN 55440-0043
Phone: 612-262-0900
Fax: 612-262-4370
GrievanceCoordinator@allina.com

You can file a grievance in person or by mail, fax or email. If you need help filing a grievance, the Allina Health Grievance Coordinator can help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>, or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Avenue, SW Room 509F, HHH Building
Washington, D.C. 20201
1-800-368-1019, 800-537-7697 (TDD)

Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>.





allinahealth.org