

# Care After Kidney Transplant



# Chapter 1: Introduction

## Introduction

Use this booklet to help you:

- and your family members adjust to life after your transplant
- prepare you to take the best care of your transplant as possible.

Write down notes, questions or concerns in this book.

Bring your book with you to any follow-up appointments to have your questions or concerns discussed.

## Your Health Care Team

You will have several health care providers working with you during your recovery and long-term follow up.

Each person has a unique role in your care.

- **Nephrologist:** He or she will see you regularly for routine exams in the Kidney Transplant Clinic and manage your medications.
- **Transplant surgeon:** He or she will see you every day in the hospital while you recover from surgery. He or she will see you after discharge as needed.
- **Transplant coordinator:** This is a registered nurse who is trained in transplant. He or she will follow you throughout your post-surgery care.
- **Pharmacist:** He or she will help manage your medications and answer questions about your medications.
- **Social worker:** He or she will help make arrangements for returning home, help find community resources and support, and answer insurance questions.
- **Dietitian:** He or she will help with questions about your diet and nutrition.
- **Primary care provider (PCP):** This is your regular doctor. Follow up with him or her for your routine health concerns and for screenings.

## Your Role in Your Health and Recovery

You are an important part of the team. There are many things you can do to have the best chance for healthy life and recovery. You will need to:

- Take your medications as prescribed. If you have questions about your medications, please ask.
- Go to scheduled doctor and nurse appointments.
- Have labs done on time and as scheduled.
- Follow diet guidelines that are prescribed for you.  
Eat a healthy diet
- Get routine screenings and vaccinations.
- Get regular exercise.
- Avoid tobacco products and illegal drugs.
- Protect yourself from infection.
- Ask questions if you don't understand something.

# Chapter 2: Recovery in the Hospital and at Home

## What to Expect in the Hospital

### After surgery

- You will be moved to the kidney floor of the hospital.
- You will be in the hospital for about 4 to 7 days depending on your recovery.
- You will have a heart monitor to closely watch your heart. It will be removed before you go home.
- You will have a Foley catheter in your bladder for several days. This will help you heal as well as let your health care team check how much urine you are making.
- You will get up in a chair and walk as soon as possible.
- You can expect some pain from the surgery site. Your pain control is important to your recovery so you will have pain medications if you need. Talk with your doctor if your pain is not under control.
- You will receive education about your transplant, recovery and follow-up.

### Education

You are an active member of your health care team. During your hospital stay you have started your physical recovery and learned a lot about your after care. Members of your transplant team have started to teach you about the following:

- medication names, purpose, doses, side effects, and when and how to make adjustments
- possible complications and how to watch for them
- lab test values and what they mean
- returning to your everyday activities
- routine and follow-up doctor or Kidney Transplant Clinic visits.

There will be many things to learn and guidelines to follow. Ask a member of your transplant team if you have any questions or concerns about any part of your transplant after care.

## **Incision care**

Your incision will remain covered for 1 to 3 days after surgery. The dressing needs to stay clean, dry and remain in place. If you have any drainage, the nurse will replace the dressing.

Tell your nurse or doctor if you have any of the following at the incision site:

- redness
- swelling
- pain
- warmth
- drainage.

After the dressing is removed, watch for signs of infection (drainage, redness, warmth) or any problems with healing. Call your transplant coordinator if you notice any problems or have concerns.

If you have staples, they will be removed about 3 weeks after surgery in the Kidney Transplant Clinic. Staples will usually be removed over the course of a few days.

If you have Steri-Strips<sup>®</sup>, let them to fall off on their own. Do not pull off Steri-Strips.

## **Supplies you need before you leave the hospital**

You will need to check and record your blood pressure several times a day, temperature twice a day and weight once every morning. If you have diabetes, you will also need to check your blood glucose as directed by your doctor. Use the logs in the “Home Monitoring” section in the back of the binder.

Make sure you have the following items before you leave the hospital and make sure they work:

- bathroom scale
- glucometer and diabetes supplies (if needed)
- accurate blood pressure cuff
- digital thermometer.

## Medications

You will also be responsible for keeping track of and taking your medications.

On the day you leave the hospital (discharge), you will get a 1 month supply of your new medications.

Some medications that you were taking before transplant may be too soon to fill and you will need to use your home supply. Your transplant coordinator will talk to you about this at discharge.

Your transplant coordinator will help you organize your medications before you leave the hospital. You will bring your medications, pill boxes and medication list to your first appointment for education and set-up.

Before you leave the hospital you should know:

- the names of your medications and why you are taking each one
- how to take them
- when to take them
- how to use your medication list to set up your medications.

## Recovery at Home After Surgery

### Activity restrictions and general guidelines

- Do not lift anything heavier than 10 pounds for 8 weeks. Your nephrologist and transplant coordinator will talk with you about any other lifting restrictions.
- Start walking as soon as possible. You will be able to increase the distance you walk every day as you recover from surgery.
- Stop doing any activity that causes you pain or discomfort.
- Do not drive until your nephrologist says it's OK.
- Do not smoke. Smoking slows your body's ability to heal. Ask your transplant coordinator if you need help quitting.
- Get enough sleep.

### Diet

- Eat a well-balanced diet low in fat, cholesterol and added sugar.
- If you have diabetes, follow your diabetes diet. Follow any special directions you receive from your doctor.
- If you have questions about nutrition and meal planning, talk with the transplant dietitian.
- See page 65 to learn more.

## **Discomfort**

The right pain control can help:

- you be more comfortable
- you get back to your normal routine
- promote healing.

Take pain medication when pain first begins. If you know your pain may get worse with activity, take your pain medication before the activity. Don't wait for pain to get worse before taking medication. Pain pills may take up to 30 minutes to work.

## **Hygiene**

- Do not take a bath until the incision is healed.
- You may take a shower.
- Pat the incision area with a clean, dry towel.

## **Travel**

- Check with your nephrologist before making travel plans.
- You should not travel for more than 3 or 4 days at a time until your doctor tells you it is OK to take longer trips.
- Most, but not all, complications such as rejection or infection occur within the first 6 months after surgery. It is important you are near your transplant team if you have complications.

## **Compliance**

Taking medications, getting labs done and going to follow-up appointments are important for good results after transplant. Your transplant team members will work with you to help you understand instructions.

Ask if you do not understand. The better you understand, the more likely you will be to follow instructions and have good results.

# Chapter 3: Medication

## Introduction

Taking medications as directed is important for your new kidney and general health. This chapter explains medications, including their use, dose and side effects. You may be prescribed medications that are not listed in the booklet.

Talk with your doctor or transplant coordinator if you have question about any of your medications.

## General Guidelines

Your medications will vary, from immunosuppressants (anti-rejection medications) to supplements (minerals). There are many different types of medications available. Your medications are prescribed to meet your needs.

The following are general guidelines to help you get used to your new routine.

- Follow the same time schedule for taking your medications each day.
- Never stop taking any medication without first talking with your nephrologist. Stopping your medication can lead to complications. Even if you are feeling well or if you had a kidney transplant many years ago, you need to keep taking your medication exactly as directed.
- Talk with your nephrologist before you start any new prescription medication, supplement, over-the-counter medication, natural product or herb. Your nephrologist needs to approve all new medications to make sure they don't change how your immunosuppressant medications work — this includes any medications prescribed by any other doctor for any reason.
- Do not take over-the-counter pain relievers (aspirin, ibuprofen or naproxen) without your nephrologist approval. You may use over-the-counter acetaminophen as directed on the package for minor aches and pains.
- Never make changes to your medication doses by yourself. Talk with your nephrologist if you have side effects or concerns.
- Side effects are possible for each medication you take. This does not mean you will have side effects. But you should understand what may happen. Talk with your nephrologist about any side effects you think may be caused by your medication.



The chance of side effects from a medication decreases as your dose is decreased. Lower doses usually cause less severe side effects.

- Do not take antacids (such as Tums<sup>®</sup>, Rolaids<sup>®</sup>, Tums<sup>®</sup> or Mylanta<sup>®</sup>) within 2 hours of taking your medication. Antacids may decrease your body's ability to absorb your regular medications.
- Do not share your medications with others.
- Do not take medications that have been prescribed for someone else.
- Keep all medications in the original prescription bottle.
- When you pick up new prescriptions, make sure the instructions match how you are taking them. If not, check with your transplant coordinator or doctor who prescribed the medication.
- In the first 6 to 12 months after transplant it is common to make frequent adjustments to your medications. Follow instructions you receive from your transplant team on how and when to take your medications. Talk with your transplant coordinator if you have any questions about your medications.
- Fill all medication prescriptions at one pharmacy, if possible.
- Do not run out of any prescription. Call for refills when you have 7 to 10 days left of any medication. It may be difficult to find a late-night pharmacy or get prescriptions filled during holidays.
- If you need to have prescriptions transferred to a different pharmacy, call the new pharmacy. Tell them what pharmacy has prescriptions you want transferred. The new pharmacy will call to have the prescriptions transferred. The Kidney Transplant Clinic nurses cannot transfer prescriptions between pharmacies.
- If your insurance changes, call your insurance provider to find out if you are required to use a specific pharmacy. If your prescriptions can be transferred, follow the directions in the bullet point above. If you cannot transfer your prescriptions or do not have refills, call the Kidney Transplant Clinic as soon as possible to help prevent running out of medication.
- If you are traveling, get any refills at least 1 week before you travel. Keep your medications with you, such as a carry-on bag if you are flying or taking a bus. Do not put your medications in checked luggage.
- Keep your medications out of reach of children or pets.

Talk with your nephrologist or transplant coordinator if you have any questions, concerns or problems with any medications, how to take them and any side effects.

[allinahealth.org/kidneytransplantbook](http://allinahealth.org/kidneytransplantbook)

## Herbal Products

- Avoid herbal products and herbal teas. The U.S. Food and Drug Administration lists these as dietary supplements. They have not been tested for side effects and interactions with medications.
- Herbal products could interact with your transplant medications. This may harm your transplanted kidney.
- Talk with your nephrologist before you take any herbal product or herbal tea.
- Avoid green and white tea as they can boost your immune system.

## Immunosuppressants (Anti-rejection Medications)

Your body has a natural defense called the immune system. It helps to protect you from things that should not be in your body such as foreign objects such as viruses, bacteria and cancer.

Your immune system sees the new kidney as foreign or non-self. Since the immune system's job is to fight off foreign objects, it wants to fight off the kidney. This is called rejection because it is your body rejecting the kidney.

**To keep your immune system from attacking the kidney, you will need to take special medications for the rest of your life. These medications are called immunosuppressants or anti-rejection medications.**

The following are types of anti-rejection medications. Your transplant coordinator will go over the medications you will be taking.

## □ Tacrolimus (Prograf®)

### ■ Use

- This medication helps prevent your body from rejecting the new kidney.

### ■ Dose

- Take this medication as prescribed.
- Take this medication once every 12 hours.
- The dose will be adjusted based on your levels and goal range.

### ■ Tips

- Never skip a dose of tacrolimus.
- You will need to have your blood levels checked on a regular basis. If the level of tacrolimus is too low, your risk of rejection increases. If the level is too high, your risk of infection and side effects increases.
- When having your tacrolimus level drawn, be sure it is as close to 12 hour trough as possible. This means that you should have your lab drawn about 12 hours after your last dose and before you take next scheduled dose.
  - For example, if you take tacrolimus at 8 a.m. and 8 p.m., you should have your labs drawn at about 8 a.m. before you take your morning dose.
- Store this medication at room temperature.
- Do not take tacrolimus with:
  - grapefruit, grapefruit juice or products that contain grapefruit juice (such as Fresca® or Squirt®).
  - pomegranates, pomegranate juice or products that contain pomegranate juice.

### ■ Side effects

- Side effects may include:
  - increased blood pressure and blood glucose
  - nausea, vomiting, diarrhea
  - slight tremors (shaking) of your hands.

## ❑ Tacrolimus (Envarsus®)

- Information is the same as tacrolimus (Prograf®) except you only take Envarsus one time a day, in the morning.
- Since Envarsus is taken only once daily, your level should be a 24 hour trough.
  - For example, if you take tacrolimus at 8 a.m., you should have your labs drawn at about 8 a.m. and before you take your morning dose.
- Your transplant coordinator will review which type of tacrolimus has been prescribed for you.

## ❑ Mycophenolate Mofetil (CellCept®)

- **Use**
  - This medication helps prevent your body from rejecting the new kidney.
- **Dose**
  - Take this medication as prescribed.
  - Take this medication once every 12 hours.
  - The dose is based on several things and will be adjusted if needed.
- **Tips**
  - Never skip a dose of mycophenolate mofetil.
  - Take the tablets whole. Do not cut, crush or break them.
  - You may be scheduled to have levels done of CellCept. This is usually done once and will include several blood draws in one day. Your transplant coordinator will give you details if you will be having this done.
- **Side effects**
  - Side effects may include:
    - decreased appetite
    - nausea, vomiting, diarrhea.

## ❑ Mychopenolate Sodium (Myfortic®)

- Myfortic is similar to CellCept.
- You may take it if you have side effects from CellCept.
- Your transplant coordinator will review which type of mycophenolate has been prescribed for you.

## ❑ Sirolimus (Rapamycin®, Rapammune®)

### ■ Use

- This medication helps prevent your body from rejecting the new kidney.

### ■ Dose

- Take this medication once a day in the morning.
- Your dose will be adjusted based on your levels and goal.

### ■ Tips

- Never skip a dose of sirolimus.
- Take this medication at the same time every day.
- Do not take with grapefruit, grapefruit juice, pomegranates, or pomegranate juice.
- Your sirolimus level should be 24 hour trough. This means your lab should be drawn about 24 hours after your last dose and before you take your morning dose of medication.

### ■ Side effects

- increased cholesterol
- headache
- tremors
- skin rash or acne
- high blood pressure
- upset stomach, nausea, vomiting, constipation, diarrhea
- low white blood cell count.

## □ Prednisone

### ■ Use

- This medication helps prevent your body from rejecting the new kidney.

### ■ Dose

- Take this medication once a day in the morning with food.
- Your dose will slowly decrease after the transplant. Your dosage will be based on a schedule called a taper. Your transplant coordinator will explain the taper schedule with you.

### ■ Tips

- Never skip a dose of prednisone.
- Follow your prednisone taper. If you are scheduled to have a decreased dose, do so on the day scheduled.
- Never take a lower dose of prednisone on your own.
- Prednisone may change your appetite and it may cause weight gain. Try to eat 3 balanced meals a day. If you feel hungry between meals, eat snacks low in calories and fat such as fruit or vegetables. Talk with your nephrologist or transplant coordinator if you need help with meal planning.

### ■ Side effects

- Side effects should be fewer or less severe with lower doses of prednisone.
- You may feel bloated because your body will retain (hold) water and salt.
- You may have mood swings while taking the higher doses of prednisone. (Call your doctor if they are severe.)
- You may have rounding of your face and a build-up of fat in your back or shoulders. This should get better with lower doses of prednisone.
- Prednisone may cause a loss of calcium. This can weaken your bones and joints. You may be prescribed a calcium supplement.
- Prednisone can increase blood glucose. This can happen if you have diabetes or not.
- If you have diabetes, you may need your diabetes medication adjusted, especially when prednisone doses are high. You should follow up with the doctor who manages your diabetes regularly.

- Other side effects may include:
  - nausea, vomiting, diarrhea
  - increased risk of infection
  - upset stomach, ulcers, heartburn or stomach bleeding
  - red or dark tarry stools
  - puffiness in face
  - muscle weakness or cramping
  - problems with wound healing
  - cataracts (cloudy vision).

## ❑ **Anti-thymocyte globulin (Thymoglobulin®)**

### ■ **Use**

- You may receive this medication to decrease your risk for rejection.

### ■ **Dose**

- You will receive your doses while you are in the hospital for your transplant surgery.
- You will receive your doses by an intravenous (IV) line.

### ■ **Side effects**

- During the infusion, you may have mild fever, chills, itching or hives. Before each infusion starts, your nurse will give you a dose of Tylenol®, Benadryl® and prednisone to try to avoid these symptoms.
- Anti-thymocyte globulin increases your body's risk for infection.

## ❑ **Basiliximab (Simulect®)**

### ■ **Use**

- You may receive this medication to reduce your risk for rejection.

### ■ **Dose**

- You will receive 2 doses while you are in the hospital.
- You will receive your doses by an intravenous (IV) line.

### ■ **Side effects**

- The most common side effects are nausea, diarrhea and constipation.

## Medications to Treat Bacterial, Viral and Fungal Infections (Antimicrobial Medications)

Antimicrobials are medications used to treat a variety of infections. The three main types of medications and the infections they treat are:

- antibiotics for bacterial infections such as urinary tract infections, strep throat, impetigo, meningitis
- antivirals for viral infections such as the common cold, chickenpox, flu, CMV (cytomegalovirus)
- antifungals for fungal infections such as thrush, candida, athlete's foot.

These medications are important because the immunosuppressants, or anti-rejection medications, lower your body's ability to fight infection.

You will be given some preventive (prophylaxis) medications to help stop infections before they start. Take these medications as directed and for the prescribed amount of time.

If you develop an infection, your doctor may prescribe medication. Follow the instructions and finish all the medication unless you are told to stop. Talk to your doctor or nurse if you have any questions.

### □ Trimethoprim and Sulfamethoxazole (Septra® or Bactrim®)

#### ■ Use

- This medication is used to treat a variety of infections (such as urinary tract and lung infections) caused by bacteria.
- Do not take this medication if you have an allergy to sulfonamides (sulfa).

#### ■ Tips

- You will start taking Septra or Bactrim on the second day after your surgery.
- Take this medication for 6 months after your transplant unless you receive other directions.



### ■ Side effects

- Side effects may include:
  - nausea, vomiting
  - loss of appetite
  - skin rash
  - increased creatinine
  - increased sensitivity to light.

## □ Dapsone

### ■ Use

- This medication is used to treat a variety of infections (such as urinary tract and lung infections) caused by bacteria. It is safe for people who have an allergy to sulfonamides (sulfa).

### ■ Tips

- Take dapsone with food.
- Dapsone may cause your eyes and skin to be sensitive to sunlight. Wear sunscreen, sunglasses and a hat when you are outdoors.

### ■ Side effects

- Side effects may include:
  - upset stomach
  - vomiting.

## □ Mycostatin (Nystatin®)

### ■ Use

- This medication is used to prevent thrush (yeast infection in the mouth).

### ■ Dose

- This is a liquid medication. You will take 1 teaspoon (5 ml) 4 times a day.
- Put this medication in your mouth and hold it for 10 to 15 seconds. Then swish it around your mouth before swallowing it.
- Do not eat, drink, brush your teeth, use a mouth rinse, or have gum or candy for 15 to 30 minutes after swallowing. This allows the medication to be absorbed and to be most effective.

- **Side effects**

- Side effects may include mouth irritation.

## □ **Valganciclovir (Valcyte®)**

- **Use**

- This medication is used to treat or prevent cytomegalovirus.

- **Dose**

- The average length of treatment is 3 to 6 months.

- Your dose will be adjusted based on your kidney function.

- **Tips**

- Take the prescription as directed by your doctor.

- **Side effects**

- Side effects may include:

- nausea, vomiting, diarrhea, constipation
    - rash.

## **Medications to Treat or Prevent Stomach and Bowel Problems (Gastrointestinal Medications)**

Gastrointestinal medications are used to treat or prevent stomach and bowel problems. These problems may be from medication side effects, illnesses, complications (problems) from surgery, or from decreased activity after surgery.

The following are types of medications used to treat stomach and bowel problems. You will not take all of them. If your nephrologist prescribes a medication not on the list, ask your nephrologist or transplant coordinator for more information.

## □ **Famotidine (Pepcid®)**

- **Use**

- This medication is used to decrease stomach acid to prevent or treat gastric ulcers.

- **Side effects**

- Side effects may include:

- abdominal discomfort
    - nausea, vomiting
    - rash.

## ❑ Omeprazole (Prilosec®)

### ■ Use

- This medication is used to decrease stomach acid to prevent or treat gastric ulcers.

### ■ Side effects

- Possible side effects are rare.

## ❑ Pantoprazole (Protonix®)

### ■ Use

- This medication is used to decrease stomach acid to prevent or treat gastric ulcers.

### ■ Side effects

- Possible side effects are rare.

## ❑ Docusate Sodium (Colace®)

### ■ Use

- This medication is a stool softener used to prevent constipation, especially right after surgery.

### ■ Tips

- Take Colace until your bowel habits return to normal then as needed for occasional constipation.
- Opioid (narcotic) pain medications, such as oxycodone, can cause constipation. If you are taking an opioid for pain, you may want to use a stool softener until you no longer need pain medication.
- Stop taking if you develop diarrhea or loose stools.

### ■ Side effects

- Side effects include abdominal cramping and diarrhea.

## ❑ Sennosides (Senna®)

### ■ Use

- This medication is a laxative.

### ■ Tips

- Take Senna until your bowel habits return to normal then as needed for occasional constipation.

### ■ Side effects

- Side effects include abdominal cramping, gas and diarrhea.

## Medications to Control Blood Pressure (Antihypertensive Medications)

Antihypertensive medications are used to control high blood pressure. High blood pressure is also known as hypertension.

There are many different kinds of blood pressure medications. Your nephrologist will prescribe the medications that are right for you.

It is not unusual to change these medications as your kidney function changes. It is important for you to closely monitor your blood pressure at home so your doctor can adjust your medication as needed. Blood pressure that is too high or too low is not good for you or the transplanted kidney.

## Nutritional Supplements (Minerals)

Nutritional supplements may be needed to add minerals to your diet. Levels of some minerals may be low due to not getting enough in your diet, side effects from medications, or both.

### ❑ Calcium With Vitamin D (OS-CAL 500 + D®)

#### ■ Use

- This supplement contains both calcium and vitamin D. Calcium is an important mineral that will help strengthen your bones. Vitamin D helps your body absorb the calcium.

#### ■ Tips

- Take this medication as prescribed.
- Take it with food.
- Do not take calcium with mycophenolate or phosphorus supplements.

#### ■ Side effects

- Side effects may include nausea, vomiting, constipation or a decrease in appetite.

## ❑ Magnesium Chloride (MagDelay®, SlowMag®)

### ■ Use

- This supplement contains magnesium, an important mineral.

### ■ Tips

- Tacrolimus can cause low magnesium level.
- Low magnesium in your blood may cause muscle cramping.

### ■ Side effects

- Side effects may include diarrhea, upset stomach and gas.

## ❑ Potassium Phosphate and Sodium Phosphate (K-Phos®)

### ■ Use

- This supplement contains phosphorus, an important mineral.

### ■ Side effects

- Side effects may include an upset stomach.

## Medications to Lower Cholesterol

These medications are given to help lower the amount of cholesterol your liver makes. Options include pravastatin (Pravachol®), atorvastatin (Lipitor®), simvastatin (Zocor®) and rosuvastatin (Crestor®).

Your doctor will prescribe one of these for you if needed.

### ■ Tips

- Take this medication at bedtime. (Your liver makes more cholesterol at night.)

### ■ Side effects

- muscle pains or aches
- rash, itching
- chest pain
- upset stomach, diarrhea
- changes in liver function tests.

# How to Read a Prescription Label

**pharmacy name, address and phone number** → Allina Health  
Allina Health Hospital Pharmacy  
920 E 28th St, Ste H2005, MINNEAPOLIS, MN 55407  
612-775-3100

**prescription number and your name** → Rx: 8-055516-16  
Patient Name

**how and when to take the medication** → Take 1 capsule by mouth 3 times daily if needed.

**name and strength of medication** → diphendramine 25 mg capsule  
Generic for: BENADRYL

**number of refills left, number of pills and the name of the company that made the pills** → No refills remaining MA/MA  
QTY: 30 capsules MFG: SANDOZ

**warnings or major side effects** → May cause drowsiness. Alcohol may intensify this effect. Use care when operating a vehicle, vessel (e.g., boat), or machinery.  
May cause dizziness  
May cause blurred vision

**what the pills look like** → pink and clear colored, oblong shaped capsule with...

**scan code** → CP [QR Code]

**the date of the prescription and your doctor's name** → 10/6/2017  
Doctor, JaneDoe

CAUTION: Federal law prohibits the transfer of this drug to any person other than the patient for whom it was prescribed.

# Chapter 4: Complications (Problems) After Surgery

## General Information

It is common to have some complications or problems after surgery. Some problems are easily treated and others are more difficult to treat.

Your body is going through many changes in the first several months after surgery. Your body will be adjusting to the new kidney and new medications. While the medications are used to protect the kidney, they may also cause some side effects or complications.

Some problems are caused by medications and will respond to changes in the medications. Other problems are not caused by medications and will need other treatments.

You will need to have frequent lab tests and Kidney Transplant Clinic appointments to check for complications. The sooner a complication is found, the sooner treatment can start.

## Delay in New Kidney Working (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 and transplant. 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 kidneys will eventually make urine and work well.

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

## Clotting Problems

Clots may form in the deep veins in your legs. These clots are known as deep vein thrombosis, or DVT. They occur right after surgery when you are not able to get much physical activity.

Symptoms of DVT include:

- swelling
- tenderness
- warmth.

To help prevent DVT, you will be:

- wearing sequential compression stockings (leggings and foot wraps) to help prevent blood clots
- given heparin, a medication to keep your blood from clotting
- encouraged to walk as soon as possible.

## Infection

The anti-rejection medications you will need to take lower your body's ability to fight infection.

You are at the greatest risk for infection several months after surgery or after any rejection episode. This is when the anti-rejection medications are at their highest doses. Infections can occur at any time.

Some of the transplant medications can lower your white blood cell (WBC) counts. WBCs fight infections. When your WBC count is low, you are at higher risk for infections. Your doctor or transplant coordinator will talk with you if your WBC count is low. Your WBC is checked regularly with your labs.

Common types of infection include:

- **bacterial** — You will take an antibiotic, (Septra® or dapson), for about 6 months after the transplant. This helps prevent a common pneumonia, urinary tract infections and some other bacterial infections.
- **fungal** — You will take an antifungal, Nystatin®, for 1 to 3 months after the transplant. This is to prevent thrush, a yeast infection, which can grow in your mouth.
- **viral** — Your transplant coordinator will talk with you if you need an antiviral medication.



## Signs of infection

Call your transplant coordinator or doctor if you have any of these signs:

- fever (temperature of more than 100.4 F)
- nasal congestion and drainage
- feeling like you have the flu (chills, aches, tiredness, headache, dizziness)
- sinus pain
- ear ache
- sore throat
- cough
- pain or burning when you urinate or feel like you need to urinate often
- bloody or cloudy urine
- skin wound that is not healing or that has redness, drainage or warmth
- upset stomach, vomiting, diarrhea.

## How to help prevent infections

You can take many precautions to help prevent infections.

- Always wash your hands with soap and water after going to the bathroom, blowing your nose, changing a diaper, handling raw meat or seafood, and before eating.
- Cover your mouth and nose with a tissue when you cough or sneeze. Or sneeze or cough into your elbow.
- Wash your hands often for at least 20 seconds each time.
- Avoid close contact with anyone who has an infection such as a cold, influenza or a cold sore.
- Avoid changing diapers, touching stool, or handling body fluids from children for 6 weeks after they have received a live virus vaccination.
- Take precautions when caring for and cleaning up after pets.
- Avoid major construction areas.
- Avoid working with soil and plants until your doctor gives approval. Soils can have fungal spores which can cause difficult to treat infections. You may be advised to wear gloves and a mask when working outside.
- If you are outdoors in wooded areas, be careful of tick bites. Wear long pants tucked into socks and long sleeves. Use insect repellent. Check your skin carefully for tick bites.

- Watch for signs of infection. Call your doctor or transplant coordinator if you have any of the signs on page 35.
- Get routine vaccinations when they are due.
- Do not swim or bathe until your incision is well healed and your nephrologist says it's OK.
- Eat a healthy diet.
- Get enough sleep.
- Talk to your transplant coordinator or doctor if you have questions about how to prevent infections.

## BK Virus

BK is a virus that can cause problems in a transplanted kidney. It is checked regularly with your labs.

If you have a BK virus infection, you likely will not have any symptoms. Your nephrologist will monitor levels and if needed, will adjust medications (usually mycophenolate). Most cases of BK improve with lowering immunosuppression.

## CMV Virus

CMV (cytomegalovirus) is a common viral infection that many people have had in the past. It usually causes mild or no symptoms. Like other viruses, once you have had it, it will stay inactive (dormant) in your body. But, if your immune system is weakened because of medications to prevent rejection, the virus could be reactivated and cause infection.

You could also pick up CMV as a new infection if you haven't been exposed before.

Levels of CMV are checked regularly after transplant. You may take a medication to prevent or treat CMV.

Symptoms of CMV infection include:

- fever
- loss of appetite
- feeling tired
- upset stomach
- diarrhea.

Tell your doctor or transplant coordinator if you have any of these symptoms.

## Lymphocele

A lymphocele is a collection of fluid around your kidney. These are seen the first couple of months after surgery. Usually, the lymphoceles are small. In time, your body will usually reabsorb the fluid and treatment is not needed.

If the lymphocele becomes large, you may:

- feel discomfort where the new kidney is placed
- have decreased kidney function
- see and feel fluid leak along the incision.

If any of the these happen, you may need a procedure to remove the fluid.

## Rejection

Rejection is your body's natural response to a foreign object. Even though the kidney was compatible, your body still sees the new kidney as foreign.

Your immune system doesn't recognize the new kidney as part of you and tries to get rid of it by attacking it. This is known as rejection.

### Preventing rejection

- Take your medications as directed.
- Never stop, start or change doses of your medications without talking to your transplant team.
- Do not take over-the-counter, herbals, vitamins or health foods without first talking to your transplant team.
- Call your transplant team if another doctor prescribes medication(s).
- Call your transplant team if you miss a medication dose. A coordinator can help get you back on track with your schedule.
- Request refills for medications 7 to 10 days before you run out to allow for refill authorizations if needed.
- Before you travel, make sure you will have enough medication for your trip, plus a few extra. If you do not, call your pharmacy to see if you can get an early refill. Some insurance companies allow for travel waivers which allow early refill. Call the Kidney Transplant Clinic to speak to your transplant coordinator if you have questions.

## Acute rejection

Most rejection episodes happen within the first few months after surgery but rejection may happen at any time. An acute rejection is a rejection that comes on quickly.

Having an acute rejection episode doesn't always mean you will lose the kidney and be back on dialysis. If caught early, many acute rejection episodes respond well to treatment.

The first signs of rejection usually show up in the lab tests. You may have some mild symptoms such as fatigue but usually you will not have symptoms until you have poor kidney function.

Watch for signs of rejection and call your transplant coordinator right away if you have any these:

- flu-like symptoms
- temperature greater than 100.4 F
- decrease urine output
- weight gain
- pain over transplanted kidney
- fatigue
- swelling (especially in your feet, ankles and hands).

The earlier a rejection is caught and treatment started, the greater the chance of a good outcome.

## Biopsy

A kidney biopsy is a test that can help your nephrologist know why your kidney is not working or not working well.

During a biopsy, a doctor will use a special tool to take several small samples of kidney tissue. A pathologist will look at the samples under a microscope and talk to your nephrologist about the findings.

Your nephrologist will talk to you about the results and if any treatment is needed.

## Treatment for acute rejection

If you have an acute rejection, your doctor will prescribe a treatment plan based on the biopsy, your history of rejection episodes, and your medical history.

Your anti-rejection medications will be adjusted. This may include intravenous (IV) medications or other treatments. These are usually given as an outpatient over several visits to the hospital.

## Chronic rejection

Chronic rejection happens when, over time, your body's immune system slowly rejects the kidney.

If this happens, you may need to go on dialysis, be evaluated for another kidney transplant, or both.

## Cancer

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

Skin cancer is the most common type of cancer in people who have had a transplant. It tends to be more aggressive in people who take immunosuppressive medications. See page 56 to learn more about skin cancer and sun precautions.

To help protect yourself, use the following guidelines.

- Have annual doctor exams and routine cancer screenings.
  - For women, this includes a Pap smear, breast and skin exams. Depending on your age and insurance coverage, you may also need a mammogram.
  - For men, this includes prostate, testicular and skin exams.
- Perform regular self-exams. Report any changes or signs of cancer to your doctor right away.

## Hyperlipidemia (Increase of Fats in Your Blood)

Hyperlipidemia is an increase of the amount of cholesterol and triglycerides in your blood. An increase of these fats can lead to heart disease.

Hyperlipidemia has no symptoms. The only way your doctor can tell if you have it is by doing a blood test. This test measures the amount of total cholesterol, LDL (bad) cholesterol, HDL (good) cholesterol and triglycerides.

You can manage hyperlipidemia with low-fat foods, weight control and regular exercise. Sometimes, doing all of the right things still doesn't lower cholesterol levels. If this happens, you and your nephrologist can decide if medications to lower cholesterol are right for you.

## High Blood Pressure

High blood pressure (hypertension) is a common problem after surgery. Left untreated, high blood pressure can cause serious problems affecting your heart, liver, kidneys and blood circulation.

Many of the anti-rejection medications cause blood pressure to rise. As the dose of those medications decrease, your blood pressure usually decreases.

Some people have high blood pressure that is not related to medications. If you have high blood pressure due to other causes, changes in your immunosuppression medication might not change your blood pressure.

It is important that you check your blood pressure as directed. High blood pressure usually has no symptoms, so it's important for you check your blood pressure regularly. Your nephrologist can prescribe medication to control high blood pressure.

## Increased Blood Glucose

Your blood glucose levels may increase after surgery. This can happen right after surgery or if you are being treated for a rejection episode because the steroid doses are at their highest during these times. With long-term use, tacrolimus and prednisone may cause increased blood glucose levels.

The rise in blood glucose may not last long or it may continue even after your anti-rejection medications are decreased.

If you already take diabetes medication, your medication(s) or dose(s) may need to be changed. If high glucose is new for you, you will need to see your primary care provider or an endocrinologist to help manage your glucose.

If you are older, have a history of prediabetes or a family history of diabetes, you are at an increased risk for diabetes after transplant.

## Osteoporosis (Weak, Brittle Bones)

Osteoporosis is a disease that causes loss of bone density. Bones become thin and weaken to the point that they break easily. Most breaks occur in the hip, spine and wrist(s).

Immunosuppressant medications can cause calcium loss from your bones. To help prevent bone loss, most people will take a calcium and vitamin D supplement. If your osteoporosis is severe, your nephrologist may refer you to primary care provider or endocrinologist.

Doing weight-bearing exercise such as walking or climbing stairs is one way to help strengthen your bones.

- Try to get 30 minutes of exercise most days.
- Your nephrologist may order a bone density scan to check for or monitor bone loss.

# Chapter 5: Transplant Clinic

## Location and Parking

The Kidney Transplant Clinic is located at 913 E. 26th St., Suite 503, in Minneapolis.

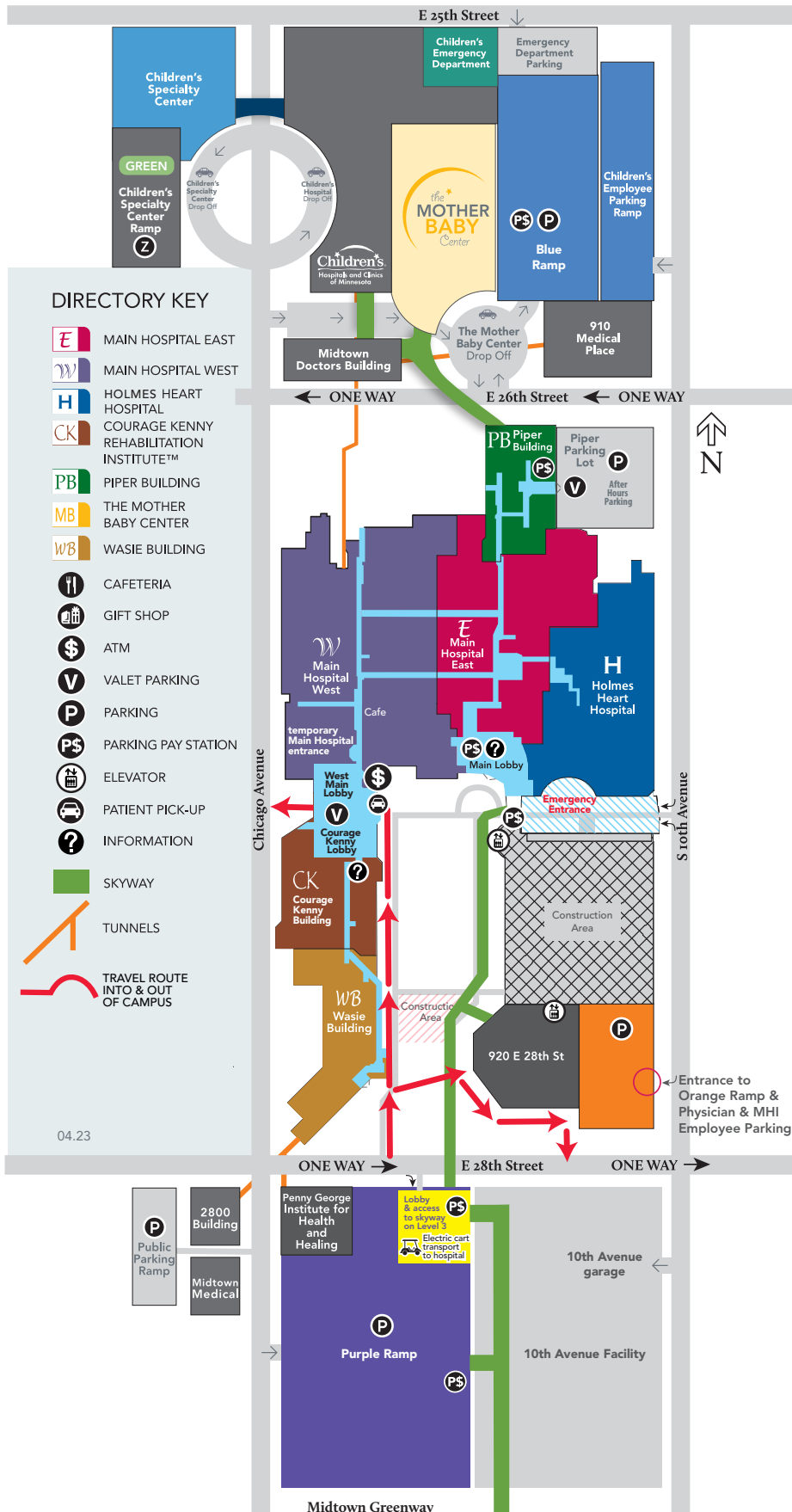
Parking is available in the parking ramps, parking lots and on the street (in designated areas). Valet service is available at the main entrance of Abbott Northwestern Hospital. Security escorts are available to walk you to your car.

## Map

See the Abbott Northwestern Hospital campus map and directions on the next 2 pages.



# Abbott Northwestern Hospital



## Directions to Abbott Northwestern Hospital

### From the east on I-94

Exit I-94 at Cedar Avenue (Exit 234C), turn left. Follow Cedar Avenue (Cedar veers to the right at the traffic lights) to E 26th Street and turn right.

■ **If visiting the Piper Building**, take E 26th Street west. Just past 10th Avenue S, take the first left for Piper parking, located between 10th Avenue S and Chicago Avenue.

■ **If visiting the Heart Hospital or main hospital**, take E 26th Street to Chicago Avenue and turn left. Proceed to E 28th Street and turn left. Turn left again onto the hospital campus.

■ **Leaving the Heart Hospital, main hospital or Piper Building**: Exit the parking ramp or lot, turning left onto 10th Avenue S and proceed to E 26th Street. Turn left onto E 26th Street and proceed to Chicago Avenue. Turn right on Chicago Avenue. Proceed to Franklin Avenue, turn left. Turn right on 5th Avenue. Proceed north on 5th Avenue to I-94 East entrance ramp.

### From the north on I-35W

Exit I-35W at the Hiawatha/Highway 55 Exit (Exit 17A). Follow Hiawatha/Highway 55 to E 26th Street. Turn right onto E 26th Street.

■ **If visiting the Piper Building**, take E 26th Street west. Just past 10th Avenue S, take the first left for Piper parking, located between 10th Avenue S and Chicago Avenue.

■ **If visiting the Heart Hospital or main hospital**, take E 26th Street to Chicago Avenue and turn left. Proceed to E 28th Street and turn left. Turn left again onto the hospital campus.

■ **Leaving the Heart Hospital, main hospital or Piper Building**: Exit the parking ramp or lot, turning right onto 10th Avenue S and proceed to E 28th Street. Turn left onto E 28th Street and follow to Hiawatha/Highway 55. Turn left and proceed to 35W North.

### From the northwest on I-94:

Exit I-94 at the Hiawatha/Highway 55 Exit (Exit 234A). Follow Hiawatha/Highway 55 to E 26th Street. Turn right onto E 26th Street.

■ **If visiting the Piper Building**, take E 26th Street west. Just past 10th Avenue S, take the first left for Piper parking, located between 10th Avenue S and Chicago Avenue.

■ **If visiting the Heart Hospital or main hospital**, take E 26th Street to Chicago Avenue and turn left. Proceed to E 28th Street and turn left. Turn left again onto the hospital campus.

■ **Leaving the Heart Hospital, main hospital or Piper Building**: Exit the parking ramp or lot, turning right onto 10th Avenue S and proceed to E 28th Street. Turn left onto E 28th Street and proceed to Hiawatha/Highway 55, turn left and follow to I-94 West entrance ramp.

### From the west on I-394:

Follow I-394 to I-94 East (Exit 8B). Exit I-94 at the Hiawatha/Highway 55 Exit (Exit 234A). Follow Hiawatha/Highway 55 to E 26th Street. Turn right onto E 26th Street.

■ **If visiting the Piper Building**, take E 26th Street west. Just past 10th Avenue S, take the first left for Piper parking, located between 10th Avenue S and Chicago Avenue.

■ **If visiting the Heart Hospital or main hospital**, take E 26th Street to Chicago Avenue and turn left. Proceed to E 28th Street and turn left. Turn left again onto the hospital campus.

■ **Leaving the Heart Hospital, main hospital or Piper Building**: Exit the parking ramp or lot, turning right onto 10th Avenue S and proceed to E 28th Street. Turn left onto E 28th Street and proceed to Hiawatha/Highway 55, turn left and follow to I-94 West entrance ramp. Follow I-94 West to I-394 West.

### From the south on I-35W

Exit I-35W at the 31st Street/Lake Street Exit (Exit 15). Proceed north on the frontage road (which is S 2nd Avenue). Turn right onto E 28th Street and proceed to Chicago Avenue.

■ **If visiting the Piper Building**, cross Chicago Avenue and turn left on 10th Avenue S (one block beyond Chicago Avenue). Go north on 10th Avenue S to the traffic light at E 26th Street. Turn left, and then immediately turn left again into the Piper Parking Lot.

■ **If visiting the Heart Hospital or main hospital**, cross Chicago Avenue and immediately turn left onto the hospital campus.

■ **Leaving the Heart Hospital, main hospital or Piper Building**: Exit the parking ramp or lot, turning left onto 10th Avenue S and proceed to E 26th Street. Turn left onto E 26th Street and proceed to Chicago Avenue. Turn left onto Chicago Avenue, proceed to E 35th Street, turn right. Proceed over the interstate and turn left immediately to enter the I-35W South entrance ramp.

### From the southeast on Hiawatha/Highway 55

Turn left off Hiawatha/Highway 55 onto E 26th Street.

■ **If visiting the Piper Building**, take E 26th Street west. Just past 10th Avenue S, take the first left for Piper parking, located between 10th Avenue S and Chicago Avenue.

■ **If visiting the Heart Hospital or main hospital**, take E 26th Street to Chicago Avenue and turn left. Proceed to E 28th Street and turn left. Turn left again onto the hospital campus.

■ **Leaving the Heart Hospital, main hospital or Piper Building**: Exit the parking ramp or lot, turning right onto 10th Avenue S. At E 28th Street, turn left. Follow E 28th Street to Hiawatha, turn right.

## Routine Visits

Kidney Transplant Clinic visits are important so the transplant team can check how well your kidney is working, check your overall health, and discuss your questions and concerns.

The number of Kidney Transplant Clinic visits you will have depends on how you are recovering and if you are having problems. Your doctor will decide when you need to go to the Kidney Transplant Clinic and your transplant coordinator will talk with you about the schedule before you leave the hospital.

On days you are scheduled to have your tacrolimus levels drawn, be sure to have your blood drawn before you take your morning medications. This is important to make sure your tacrolimus levels are accurate. Bring your morning medications and breakfast with you. After your blood is drawn, you will be able to take your medications and eat.

**All follow-up visits and lab checks are important. Please keep any appointment, no matter how you feel. If your body is rejecting the kidney, the first signs will show up in the lab results. By the time you don't feel well, the rejection may be severe and more difficult to treat.**

Your transplant coordinator will give you instructions for your first follow-up appointment when you are discharged from the hospital. A list of upcoming appointments will also be given to you before discharge. A general schedule is:

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.**

## Labs

- Labs should be done the day of your appointment during the first several months after transplant.
  - When you come in for your appointments only once a year, have your labs drawn a few days before your appointment. Your doctor can talk with you about your results when he or she sees you in the Kidney Transplant Clinic.
- Labs will often include checks of your tacrolimus, cyclosporine and rapamycin levels. Check with your transplant coordinator if you are unsure if a level is being drawn.
  - Your levels should be drawn before your morning dose of medication.
- You may need to give a urine sample at the lab. Check with lab staff before using the bathroom at the lab.
- You may need to have a special test to check your CellCept® (mycophenolate) level. This test requires 3 labs to be drawn on one day. Your coordinator will review this with you in more detail if you will be doing this test.

## Stent and Stent Removal

During transplant surgery, the surgeon placed a small tube called a stent in the donor ureter. The ureter drains urine from the kidney to the bladder. The stent keeps the ureter open to prevent urine from backing up into the transplanted kidney. It also helps support the incision during healing.

Your coordinator will schedule the appointment for the removal and review instructions with you.

Before the stent is removed, you will need to take a preventive antibiotic. Your doctor will prescribe it and your nurse will explain how and when to take it.

The stent removal procedure only takes a few minutes. It is similar to having a Foley catheter inserted.

After the stent is removed, most people do not need another one. If you do, your nephrologist will talk with you about it and answer your questions.

## Unscheduled Hospital Stays or Doctor Visits

If you have a medical emergency and need to stay in the hospital or visit a clinic that isn't your regular one, be sure to tell the health care providers that you have had a kidney transplant.

Let your nephrologist know where you went, why, who you saw, and what happened.

It is important that you have your medical records from these visits sent to the Kidney Transplant Clinic.

# Chapter 6: Returning to Your Normal Activities

## Diet and Maintaining a Healthy Weight

There are many benefits to maintaining a healthy weight. Being a healthy weight helps to control your blood pressure, cholesterol and blood glucose levels.

The body mass index (BMI) is a measure of body fat based on height and weight. The results tell if you are underweight, normal weight, overweight or obese.

According to the National Institutes of Health, BMI ranges are:

- underweight: less than 18.5
- normal: 18.5 -24.9
- overweight: 25-29.9
- obese: 30 and higher.

How to maintain a healthy weight:

- Eat well balanced meals and snacks that are low in fat, cholesterol and added sugar.
- If you have diabetes, continue to follow your diabetes diet.
- Avoid foods that are high in calories.
- Eat only when you are hungry, not out of habit.
- Exercise every day.

## Exercise

Exercise can help with healing and help you to feel better. After surgery you should start exercising slowly, even if you exercised before surgery.

Do not lift more than 10 pounds for first 6-8 weeks. You may slowly begin to lift more weight after 8 weeks.

Exercise guidelines:

- Walking is great low-impact exercise.
- Try to get 30 minutes of aerobic exercise every day. Aerobic exercise, such as walking and bicycling, will:
  - lower your heart's workload by decreasing your heart rate and blood pressure
  - increase your metabolism of fats and lower your blood lipids (cholesterol)

- improve your blood circulation
- lift your spirits
- keep your weight down
- help you handle stress.

- If getting 30 minutes of exercise is difficult because of limits (such as time or arthritis), split up the 30 minutes into 10 or 15 minutes a time. It still counts!
- Put ice on painful joints or warmth on painful muscles before and after you walk. Stretching is a good idea, too.
- Avoid any type of exercise that could cause trauma to your new kidney, such as contact sports.
- If you are thinking about running, talk with your nephrologist first. Although running is excellent exercise, it can be stressful on your bones. (A side effect of taking prednisone is bone loss.)

## Driving

- You will not be able to drive for several weeks after surgery.
- You cannot drive while you are taking an opioid (narcotic) pain medication.
- Your nephrologist will let you know when it is OK to drive again.

## Primary Care Provider

Your primary care provider (PCP) will continue to be an important part of your health care team. See your PCP for:

- routine visits and physical exams
- cancer screenings
- vaccinations
- any health care concerns you may have that are not related to your kidney transplant.

If you do not already have a PCP, it is recommended that you make an appointment to establish care with a provider. If you have questions about how to find a PCP, ask your transplant coordinator.

## Dental Care

Taking care of your teeth is important. The anti-rejection medications can have side effects that affect your dental health.

**It is important that you visit your dentist and dental hygienist as recommended for regular checkups and cleanings.**

The most common dental problems after a transplant are:

- gum disease
- tooth decay
- mouth ulcers
- dry mouth
- infections.

You do not need to take an antibiotic before your dental appointment because of your kidney transplant. Follow routine guidelines for preventive antibiotics. Call the Kidney Transplant Clinic if you or your dentist have questions.

If you have dentures, have your mouth checked by a dentist at least once a year. The dentist should make sure the dentures fit properly and check your mouth for cancer.

### **What to do if you do not have insurance**

Talk with your social worker if you do not have dental insurance. You may be able to get an appointment at a low-cost dental clinic through a dental school or at a community health clinic.

## Eye Care

Eye exams are important to check your vision and health of your eyes. Talk with your eye doctor about how often you should have eye exams.

If you have diabetes, you should have one dilated eye exam at least once a year. A dilated eye exam is done by an eye doctor (ophthalmologist). Eye drops are placed in your eyes to make the pupil large so the doctor can see inside your eyes.

A dilated eye exam can find serious problems such as glaucoma, cataracts, diabetes, infection, and cancer. Talk with your eye doctor if you have questions about your eye exams.



## Immunizations (Vaccinations)

It is important to stay up-to-date on vaccinations. Check with your primary care provider or pharmacist if you have vaccinations that need to be updated.

Here are routine guidelines for some common vaccinations:

- influenza: every fall
- Td or Tdap (tetanus, diphtheria, pertussis): every 10 years
- Pneumovax<sup>®</sup> (pneumonia): every 5 years
- Prevnar<sup>®</sup> (pneumonia): one time
- Shingrix<sup>®</sup> (shingles): one time series of 2 shots
- hepatitis B: series often given before transplant. Check with your nephrologist or transplant coordinator to see if you need this series.

Check with your nephrologist before getting a vaccination. While some (like the ones listed above) are safe to get after a transplant, others may not be if they contain a live virus.

## Sun Precautions

There is an increased risk of skin cancer in all transplant recipients. If found and treated early, many skin cancers can be treated successfully. For this reason, it is important for you to do the following:

- See a dermatologist at least once a year. If you do not have a dermatologist, talk to your transplant coordinator who can help you find one.
- Do regular skin checks as recommended by your dermatologist.
- If you see any changes in skin or new skin growths, check with your dermatologist or PCP right away. The sooner a skin cancer is found, the better the chance of successful treatment.
- Limit the amount of time you spend in the sun.
- Wear broad spectrum sunscreen with SPF of at least 30 all year.
  - Apply it to all skin that will be exposed to sun.
  - Apply sunscreen 30 minutes before going out during the day and reapply it every 2 hours and after swimming or sweating.
- Wear protective clothing including hats, whenever possible.
- Avoid being in the sun between 10 a.m. and 2 p.m.
- **Do not sun bathe or use tanning beds.**

## Alcohol

It is best to avoid alcohol because it may affect the way your body absorbs tacrolimus. An occasional alcoholic drink is OK but it is recommended that you limit how much alcohol you drink.

## Illegal Drugs

Illegal drugs (such as cocaine, crack, heroin, marijuana, ecstasy) are harmful. They are especially harmful to a person who has had a kidney transplant.

Marijuana is known to carry a fungus that causes aspergillosis, an infection that can lead to:

- fever
- cough or wheezing
- coughing up blood or mucus
- worsening asthma
- death (severe cases).

Talk with your transplant coordinator, doctor, counselor or other health care provider if you have had or currently have drug addiction. You may benefit from counseling, support programs or both.

## Tobacco Use

Avoid all tobacco use. Smoking can:

- damage blood vessels, including those that supply blood to the new kidney
- cause heart disease, stroke and cancers
- increase your heart rate, blood pressure and workload of your heart
- increase your risk of osteoporosis
- delay your healing from surgery.
- Smokeless tobacco and e-cigarette products are not safe alternatives to smoking.

Talk with your nephrologist or transplant coordinator if you need help quitting tobacco. (See page 80 for resources.)

## Returning to Work or School

Your recovery and the type of work you do will determine when you can return to work. Ask your nephrologist when you can go back to work or school.

In general, you should be able to return to work or school in about 6 to 8 weeks. You may be able to return sooner if your job doesn't involve a lot of physical activity. You may need more time to recover if you have a job that involves physical activity.

If you received disability benefits for kidney failure before transplant surgery, you will not be able to receive those benefits now with a working kidney.

If you received disability based on other health issues, you may still be eligible to receive those benefits. Talk with the financial specialist, social worker or human resources representative at your company if you have questions.

## Sexuality

You should feel better and have more energy after surgery. You can continue sexual activity once your incision is healed and you feel comfortable.

Menstrual cycles for women may return to normal within a few months to one year after transplant. Men may notice improvements in erections in a few months after transplant.

## Pregnancy

It is possible to have children after a kidney transplant.

### Women

- Wait at least 1 year after a transplant before trying to become pregnant. Talk with your nephrologist before becoming pregnant so that your medications can be adjusted.
  - **Some medications can harm an unborn child. Mycophenolate (CellCept®) can cause major birth defects. Do not become pregnant while taking CellCept or for several months after stopping due to the risk to the unborn child.**
- If you think you are pregnant, call your PCP right away so you can get a pregnancy test. If the test is positive, call the Transplant Clinic right away to see if any medications need to be changed.

- If you don't want to become pregnant, see your OB/GYN for birth control options. Call the Transplant Clinic before you start taking any medications.

### Men

- You should talk to your nephrologist before fathering a child.

## Travel

If you are planning to travel, talk with your nephrologist before you make your arrangements. Follow these general guidelines.

- Avoid major travel for the first few months after surgery.
- Always keep extra doses of your medication with you when you travel in case you are delayed or miss a plane, train or bus.
- Keep your pharmacy's phone number with you.
- Never pack your medications in your luggage. Always carry them with you so they do not get lost or exposed to temperatures that are too hot or too cold.
- Many pharmacies can ship your medications if you are away from home for a long time. Check with your pharmacy before you leave.

If you travel to another country, follow these guidelines:

- Check to see if you need any vaccinations (shots) for the country you will be visiting. Your doctor can tell if all of your vaccinations are up to date.
  - Check with your insurance provider to see if a visit to a travel clinic is covered. The travel clinic can review your vaccinations and recommend any that may be needed.  
**Remember: you can't get any live vaccinations.**
- Carry a letter from your doctor about your medications in case you have any problem with customs when traveling overseas. You may be able to fill your prescription in a pharmacy at your travel destination. Check with your insurance provider before you leave.
- Call for refills at least 1 week before you travel to allow for refill authorizations if needed.
- Keep your medications in a carry-on bag. Should there be flight delays or if your luggage is lost, you will still have your medications.
- When you are traveling, make sure the water you drink is properly treated and all food is properly cooked.
- Consider wearing a medical alert bracelet or necklace.

## Drinking Water

- Drinking treated city tap water after a kidney transplant is safe.
- Consider using bottled water for drinking if you have well water.
- Call your local health department for advice on how to have your well water tested.
  - If you drink well water, use a 1 micron filter.

## Handling Food

- **Important:** Safe food handling is important. You are at a higher risk of getting a food-borne illness because your immune system can't fight infection as well.
  - Avoid raw or undercooked meat, fish (sushi, oysters), poultry or eggs.
  - Check "sell by" dates on meats, fish and dairy products.
  - Avoid eating from salad bars or buffets. There could be issues of possible contamination or unsafe temperatures.
  - Avoid foods from street vendors.
- When preparing food, use these guidelines:
  - Thoroughly cook raw meat (beef, pork or poultry).
  - Wash raw vegetables well before eating.
  - Keep uncooked meats separate from vegetables and from cooked foods and ready-to-eat foods. (Keep them separated in your grocery cart, too.)
  - Do not eat or cook with unpasteurized milk or foods made from unpasteurized milk.
  - Wash your hands, knives, cutting boards and any surface that may have come in contact with uncooked food before working with a different food item.
  - Never thaw foods at room temperature.
  - Refrigerate foods quickly.
  - Plan shopping trips so you can refrigerate foods within at least 2 hours of purchase.

## Handling Pets

Pets are an important part of family life. Animals can help relieve stress and may improve a person's quality of life. Follow these guidelines if you have pets to lower your risk of getting an infection from your pet:

- Wash your hands after petting or playing with your pet, especially before you eat or handle food.
- Make sure your pet gets regular health checkups and required vaccinations.
- Do not let your pet lick your face.
- Avoid cleaning fish tanks. If you must, wear disposable gloves.
- Avoid stray or sick animals.
- The Centers for Disease Control and Prevention considers the following pets high-risk and should be avoided:
  - reptiles (including lizards, snakes and turtles)
  - baby chicks and ducklings
  - exotic animals.
- Do not change a cat litter box. If this is not possible, wear gloves and a face mask, and clean the box every day. Wash your hands well after changing the litter box. (The same applies to birds and pet turtles.)
- If you are bitten by an animal, call your PCP right away.

## Gardening

When working outdoors, use these guidelines:

- Talk with your nephrologist before you begin gardening to see if it's OK for you to work in your garden.
- Wear gloves when you handle soil. This will keep you from coming in contact with droppings from cats, birds or other animals.
- You may be advised to wear a mask.
- Avoid working with compost piles, wet leaves and rotting organic matter. They may contain mold, which can increase your risk for respiratory infections.
- Wash your hands well after working in the garden.

## Mental Health

The transplant process can be a positive and rewarding experience, but it can also be overwhelming. You have new medications, home tests, Kidney Transplant Clinic visits, side effects, and other changes.

Don't be afraid to talk to family members, friends or members of the transplant team about your feelings, problems, concerns or questions.

Ask your social worker or transplant coordinator for more information if you or family members need to speak with a mental health provider.

# Chapter 7: Diet

## Introduction

After transplant, you may be instructed to increase or decrease the amount of certain things in your diet. Sometimes this is because of a medication side effect or it may be due to eating too much or not enough of certain foods.

For example, tacrolimus can cause low levels of magnesium in your blood. If you have low magnesium, you will be encouraged to eat foods that are high in magnesium.

See the lists of magnesium, potassium and phosphorous foods on the following pages. Your nephrologist or coordinator will talk to you about which foods you should eat more of and which foods you should avoid. Talk to your nephrologist or coordinator if you have questions.



# Chapter 8: Home Monitoring

## Vital Signs

### Blood pressure

- Check your blood pressure 2 to 4 times a day. Record the date and time of each reading.
- Each person's "normal" may be different.
- Your nephrologist will review your blood pressure readings and adjust your medications if needed.

### Temperature

- Check your temperature 2 times a day.
- Use a digital thermometer.
- Do not check your temperature within 5 minutes of drinking or eating hot or cold beverages or foods.

### Weight

- Check your weight once every day.
- Weigh yourself at the same time, on the same scale and with the same amount of clothing.

### Diabetes

- If you have diabetes, you will receive instructions how to monitor your blood glucose.
- It is very important to follow with the doctor who manages your diabetes. Some transplant medications can increase your blood glucose and you may need your diabetes medication adjusted.

## When to Call the Kidney Transplant Clinic

Call the Kidney Transplant Clinic if:

- the top number of your blood pressure is more than 160 or the bottom number is more than 90 three times in a row
- your blood pressure reading is very different from your usual readings
- your temperature is more than 100.4 F
- you have nausea, vomiting or diarrhea
- you don't feel well in general.

Use the worksheets in the Home Monitoring chapter of this binder. Bring this booklet with your tracking logs to your Kidney Transplant Clinic appointments.

# Chapter 9: Glossary of Lab Tests

## Glossary of Lab Tests

If you have blood drawn at another clinic, have the lab send a copy of the results to you. You will be having lots of lab tests.

The following is a list of common lab tests. Ask your nephrologist or transplant coordinator if you have questions.

Test	What it is
<b>Albumin</b>	It is a protein made in your liver. This blood test checks how well your liver is working.
<b>Alk p-tase (alkaline phosphatase)</b>	It is an enzyme in your body. This blood test can help tell how well your liver is working.
<b>AST (aspartate amino transferase)</b>	It is an enzyme in your body. This blood test can help tell how well your heart, liver and kidneys are working.
<b>Bicarbonate</b>	It is an electrolyte that helps control the amount of acid in your blood. This test checks the acidity level of your blood.
<b>Bilirubin</b>	It is made when red blood cells break down at the end of their life cycle. Your liver filters it out of your body. This blood test checks how well your liver is working.
<b>BUN (blood urea nitrogen)</b>	It is a waste product in your blood. Your kidneys filter it out of your body. This urine test checks how well your kidneys are working.
<b>Calcium</b>	It is needed for your muscles to tighten, heart to work, blood to clot, and nerves to work. This blood test checks the calcium level in your body.
<b>Chloride</b>	It is an electrolyte and works with sodium to influence your water balance. This blood test checks the chloride in your body.
<b>Cholesterol</b>	It is a fat substance made in your body and found in certain foods. It is important for energy, making hormones, making bile acids and cells. High levels can cause clogged arteries and a higher risk of heart disease. This blood test checks the total cholesterol in your body.

Test	What it is
<b>Creatinine</b>	It is a waste product in your blood. Your kidneys filter it out of your body. This blood test checks how well your kidneys are working.
<b>Creatinine clearance</b>	This test measures creatinine levels in both a sample of blood and a sample of urine from a 24-hour urine collection. The results are used to calculate the amount of creatinine that has been cleared from the blood and passed into the urine. This calculation allows for a general evaluation of the amount of blood that is being filtered by the kidneys in a 24-hour time period.
<b>Glucose</b>	It is the energy source that helps your body cells to live. It is formed when your food digests (breaks down). Your body makes insulin to keep the glucose level in check. This blood test checks the glucose level in your body.
<b>HDL (high density lipoprotein)</b>	It is the “good” cholesterol that carries cholesterol from your blood to your liver. This blood test checks the HDL level in your body.
<b>Hematocrit</b>	Hematocrit means “to separate blood.” This blood test tells the percentage of red blood cells in your blood.
<b>Hemoglobin</b>	It is the main part of red blood cells. It helps deliver oxygen to your cells. This blood test measures your blood’s hemoglobin level.
<b>LDL (low density lipoprotein)</b>	It is the “bad” cholesterol that carries cholesterol to your body’s cells. High levels of LDL can narrow blood vessels. This blood test checks the LDL level in your body.
<b>Magnesium</b>	It is a mineral you need for energy, to build proteins, help your muscles work, and help your blood clot. This blood test checks the magnesium level in your body.
<b>Phosphorus</b>	It is a mineral you need for bones and body cells to live and grow. This blood test checks the phosphorous level in your body.

Test	What it is
<b>Platelets</b>	These blood cells are needed to help your blood clot. When levels are low, you can have bleeding that is difficult to stop. This blood test checks the level of platelets in your body.
<b>Potassium</b>	It is an element (electrolyte) that helps your heart maintain a regular heartbeat. Your kidneys control the amount of potassium in your blood. This blood test checks the level of potassium in your body.
<b>Protein</b>	It is important to keep your cells and muscles healthy. This blood test checks the level of protein in your body.
<b>PSA (prostatic specific antigen)</b>	It is a protein that is made by the prostate gland in men. When a man's prostate is enlarged or has prostate cancer, the PSA level can become high. This blood test checks the level of PSA in your body.
<b>Sodium</b>	It is an element (electrolyte) that causes your body to hold (retain) fluid. Your kidneys control the amount of sodium in your blood. This blood test checks the level of sodium in your body.
<b>Triglycerides</b>	It is a fat substance made in your liver. It is important for giving you energy. High levels can cause clogged arteries and a higher risk of heart disease. This blood test checks the triglyceride level in your body. It may mean you are having problems with your liver or pancreas.
<b>Uric acid</b>	Uric acid is a waste product in your blood. Your kidneys filter it out of your body. This test checks the level of uric acid in your blood.
<b>White blood cell count</b>	These blood cells help your body fight off infections. This blood test checks the level of white blood cells in your body.

# Chapter 10: Resources

## Resources

If you find information on a website, show it to your transplant coordinator. If you find a website that asks for you to register or that sells information or products and you are unsure about it, ask your transplant coordinator.

- **Allina Health**  
allinahealth.org
- **LifeSource**  
life-source.org
- **United Network for Organ Sharing**  
unos.org
- **Medic Alert**  
medicalert.org
- **National Kidney Foundation**  
kidney.org
- **Medicare**  
medicare.gov or 1-800-638-6833
- **The Organ Procurement and Transplantation Network**  
optn.org
- **Your Prescription for Transplant Information**  
transplantliving.org
- **Find Out How to Become an Organ and Tissue Donor**  
donatelife.net
- **Department for Health and Human Services**  
organdonor.gov
- **National Transplant Assistance Fund**  
transplantfund.org
- **International Transplant Skin Cancer Collaborative**  
itscc.org

## Quitting Tobacco Resources

For information on quitting tobacco, see the [Resources list](#).