

# **After Your Kidney Transplant**

## **What You Should Know**

**Beaumont**



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# Chapter 1

## Introduction

Congratulations on receiving your kidney transplant. Taking care of yourself and your transplant requires a lifetime commitment from you. This booklet is designed to help you with that commitment.

The transplant team includes nurses, doctors, a dietitian, pharmacist, financial coordinator and social worker. You also are expected to be an active part of the transplant team. As part of the transplant team, you will need to:

- talk to your transplant team regularly
- take your medications as prescribed
- keep to your schedule of clinic visits and lab tests
- check your weight, temperature and blood pressure as ordered
- maintain a healthy lifestyle (for example, a healthy diet and no smoking)

We expect you will have many questions after your transplant.

Your transplant nurse will be your main contact for questions after your transplant.

Our nurses are registered nurses who specialize in transplantation. They will be able to answer most of your questions. When necessary, your transplant nurse will talk with other team members to get your questions answered.

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## Beaumont Multi-Organ Transplant Clinic telephone list

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Medical Office Building  
3535 West 13 Mile Road  
Suite 644  
Royal Oak, MI 48073

Office: Monday through Friday,  
8 a.m. to 4:30 p.m.  
248-551-1010, or 800-253-5592  
Medication refill line: 248-551-3434

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### Support staff

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Sandy LaDuke  
Ann Stemas  
Dawn Beltowski  
Erica Threadgill  
Susan Morgan  
Eulona Guzi

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### Post-transplant nurse coordinators 248-551-1010

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Pat Garland, RN  
Kelly Hendrix, RN  
Beverlee Schoenherr, RN  
M. "Irene" Uy, RN  
Danielle Lodato, RN

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### Pre-transplant nurse coordinators (kidney)

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Joan Rappley, RN  
Amy Pavlakos, RN  
Kimberley Smith, RN  
Erin Uhrig, RN  
Renautta Wojtylo, RN

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### Kidney outreach coordinator

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Jennifer Fogarty, RN

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### Transplant surgeons

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Alan Koffron, M.D.  
Steven Cohn, M.D.  
Daman Bedi, M.D.

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### Transplant nephrologists

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Dilip Samarapungavan, M.D.  
Ekamol Tantisattamo, M.D.  
Raghavesh Pullalarevu, M.D.

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### Transplant social workers

---

Susan Walker, LMSW  
248-551-9897

Sophia Awan, LMSW  
248-551-1201

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### Transplant pharmacist

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Maxine Ng, PharmD, BCPS  
248-898-2661

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### Transplant financial coordinator and transplant financial representative

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Angelia Harris  
248-551-0771

Maria "Terri" Trepanier  
248-551-0077

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### Transplant dietitian

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Jill Jensen, R.D., CNSC

Problems and concerns after  
4:30 p.m. Monday-Friday,  
weekends and holidays, please  
call 248-898-5000. Ask the  
operator to page the transplant  
nephrologist on call.

# Chapter 2

## Medications

You will be on many different medications after your transplant. These include anti-rejection medications (or immunosuppressants), antibiotics, antivirals, antifungals and other medications based on your individual case. For example, you may need medication to lower your blood pressure or blood sugar.

It is critical to take these medications as prescribed. Even little changes from what the doctor prescribed can harm you and your kidney.

This chapter will list some of the medications you will be taking and their side effects. Talk to your transplant doctor, nurse or pharmacist if you have questions about:

- when and how to take your medications
- what to do if you forget a dose
- where to get your medications
- how to get medications if you don't have enough money to afford them

It is very important to take all medications exactly as directed. Sudden changes in dosages may lead to serious complications. You must follow the directions for your medications and write down changes that are made by the physician. This is vital to the success of your kidney transplant.

It is important to learn about your medications including:

- the name
- the purpose of the medication
- the dose/strength
- when to take each one
- possible side effects

**It is helpful to always carry a list of all your current medications.**

Continue to follow these rules after your kidney transplant:

- Keep a record of all the medications you take (including the dose and how frequently you take it).
- Take all your medications exactly as directed.
- Report any side effects to your transplant nurse, doctor or pharmacist.
- Do not take any over-the-counter medications, vitamins or herbal remedies without talking with your doctor first.
- Some medications interact with immunosuppressants and could harm your transplanted kidney. If you are prescribed a medication by a doctor other than your transplant doctor, check with your transplant team to make sure that it is okay to take.
- Call your pharmacist for refills at least one week before you are due to run out of your medication. Also make sure you will have enough medication with you if you will be away from home.
- Store your medications in a cool, dry place away from direct sunlight.
- Notify your transplant team immediately if you are unable to take your medications by mouth because you are sick, nauseous or vomiting.
- Ask for prescriptions for medication refills at your clinic visits.
- If you miss a dose of your medication, call your transplant nurse coordinator or physician for advice. Do not double the dosage.

**The most important thing to remember is to take the right dose of your medication at the right time.**

### **Your medication schedule**

Before you go home, you will be given a medication chart that will help you keep track of your medications. Always keep this sheet with your records and bring it with you to all of your Transplant Clinic visits.

During the first few months after transplant, there will be frequent medication changes. Please update your medication sheet using a pencil so changes can be made easily.

More information about your medications and possible side effects are on the following pages. You will also meet with a pharmacist for more detailed information about your medications before you are discharged from the hospital.

Remember, while we list many possible side effects of your medications, you may experience only a few of them or you may not have any at all. If you do notice any side effects, tell your transplant nurse or doctor during your clinic visit. If any side effect becomes worse for you and you believe that you cannot wait for your next appointment to tell the transplant team, please call your transplant nurse.

## Immunosuppressants

The following is a list of anti-rejection (immunosuppressant) medications that are the most common medications that kidney transplant patients take. Based on your individual case, you may be on a combination of one, two or three different immunosuppressant medications. You will take these medications for as long as your kidney transplant is working. These medications help to prevent rejection.

### Transplant medications

Generic name	Brand name
tacrolimus	Prograf
prednisone	Deltasone
mycophenolate mofetil (or an alternate formulation, mycophenolic acid)	Cellcept (or an alternate, Myfortic)

**Do not change the dose or stop taking these medications unless you have talked to your transplant doctor or nurse.**



## Detailed immunosuppressant information

<b>Tacrolimus (Prograf)</b> <i>Do not change the dose or stop taking this medication unless you have talked to your transplant doctor or nurse.</i>	
Purpose	<p>Tacrolimus helps prevent transplant rejection by reducing the number of blood cells that are part of the rejection process. You will take this medication for as long as your kidney transplant is working.</p> <p>In some cases, because of side effects, patients must take an alternative medication, such as cyclosporine or sirolimus. If this is the case, you will be educated about this new medication.</p>
Dosing	<p>The capsules come in the following sizes: 0.5 mg, 1 mg and 5 mg</p> <p>The medication is taken twice a day, 12 hours apart, in order to keep the medication at an even level in your blood.</p>
Monitoring	<p>Your dose of tacrolimus will be based on your weight, the level of medication in your blood, and any side effects that you may have. Therefore, on the day of your scheduled lab draw or clinic visit, do not take your morning dose of tacrolimus until your labs have been drawn. Bring your dose of medication to clinic with you to take as soon as your blood has been drawn. Your blood should be drawn about 12 hours from your last evening dose.</p>
Precautions	<p>Tacrolimus may interact with some commonly used prescription medications (such as certain antibiotics), over the counter medications and herbal products. Always check with your transplant physician or nurse coordinator before starting a new medication.</p> <p>Do not use any pain medication besides Tylenol unless instructed by your physician.</p> <p>Medications like Ibuprofen (Motrin, Advil) and Naproxen (Naprosyn, Aleve) should be avoided as they may put stress on your kidneys when taken in combination with tacrolimus.</p>

<p>Precautions <i>continued</i></p>	<p>Some fruits may alter the way that your body absorbs tacrolimus. These include grapefruit and pomegranate in any form (fresh or canned fruit and any juices made with pomegranate or grapefruit). Some examples of juices that include grapefruit are Squirt, Fresca, Sunny Delight, Sundrop and Five Alive.</p> <p>Any immunosuppressant medication will lower your body's defenses against cancer. Skin cancer is the most common cancer seen after transplant. Tacrolimus may increase your risk for developing certain cancers that affect the lymph nodes. See the section of this booklet titled "Cancer Precautions" for more information.</p> <p>Missing a dose of tacrolimus may allow your body to recognize the new organ as foreign and cause a rejection episode. Call your transplant doctor or nurse coordinator for further direction if you miss a dose or if you take too much tacrolimus.</p>
<p>Common side effects</p>	<ul style="list-style-type: none"> <li>▪ lowered resistance to infection</li> <li>▪ tingling, numbness or tremor in your hands or feet</li> <li>▪ high blood sugar (which may require medication for diabetes)</li> <li>▪ high blood pressure</li> <li>▪ high cholesterol</li> <li>▪ high potassium levels</li> <li>▪ changes in kidney function</li> <li>▪ headache</li> <li>▪ hair thinning or hair loss (usually temporary)</li> <li>▪ nausea, vomiting or diarrhea (if you are unable to keep fluids and/or your medication down, go to the Emergency Center at Beaumont for treatment)</li> </ul> <p>Some of these side effects may go away with time or with a dose adjustment by the physician. The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator.</p>

<b>Prednisone (Deltasone)</b> <i>Do not change the dose or stop taking this medication unless you have talked to your transplant doctor or nurse.</i>	
Purpose	Prednisone helps prevent rejection by reducing inflammation and antibody production.
Dosing	<p>Prednisone can be given intravenously or in pill form. It reduces inflammation and antibody production. By reducing antibodies, prednisone helps prevent rejection or control rejection if it has already started. You will be given 10 mg tablets of prednisone and a calendar of how much to take each day.</p> <p>Certain patients may take little or no prednisone long-term. The transplant nephrologist will make this determination.</p>
Precautions	<p>Do not stop taking prednisone abruptly. It must be gradually decreased.</p> <p>Do not take prednisone on an empty stomach as it may cause stomach irritation and/or ulcers. Report bright red or black stools or vomiting blood.</p> <p>At higher doses, prednisone may increase your appetite. To help prevent weight gain, follow a healthy diet and establish an exercise program approved by your physician.</p> <p>Prednisone is a steroid and can cause water retention (swelling in the legs, feet or abdomen). Follow a low-salt diet, as instructed by the dietitian. Tell your transplant physician or nurse coordinator if you gain two pounds overnight or five pounds in a week.</p> <p>Prednisone can cause high blood sugar. If you are already diabetic, your insulin dose may have to be adjusted. Monitor your blood sugar four times a day.</p> <p>If you are not a known diabetic, watch for signs of high blood sugar:</p> <ul style="list-style-type: none"> <li>▪ increased thirst</li> <li>▪ increased urine output</li> <li>▪ headache or blurred vision</li> </ul> <p>If your blood sugar remains high, you may require medication for diabetes.</p>

<p>Precautions <i>continued</i></p>	<p>Mood swings are common with prednisone. You may feel angry, sad, irritable, anxious or energetic. This effect usually improves as the prednisone dose decreases.</p>
<p>Common side effects</p>	<ul style="list-style-type: none"> <li>▪ lowered resistance to infection</li> <li>▪ increased blood pressure</li> <li>▪ high cholesterol</li> <li>▪ acne</li> <li>▪ insomnia/sleep disruption</li> <li>▪ “moon face” (fatty deposits in the face)</li> <li>▪ blurred vision</li> <li>▪ cataracts or glaucoma</li> <li>▪ brittle bones</li> <li>▪ joint pain</li> <li>▪ muscle weakness</li> <li>▪ increased risk of skin cancer</li> </ul> <p>Some of these side effects may go away with time or with a dose adjustment by the physician. The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator.</p>

<b>Mycophenolate mofetil (CellCept) or Mycophenolic acid (Myfortic)</b>	
Purpose	<p>This medication (you will be given one or the other) works by reducing the number of blood cells that are part of the rejection process.</p> <p>Mycophenolic acid is enteric coated and is absorbed differently by the body.</p>
Dosing	<p>The medication is taken twice a day, 12 hours apart, in order to keep the medication at an even level in your blood.</p> <p>CellCept comes in 250 mg capsules and 500 mg tablets. Myfortic comes in 180 mg and 360 mg tablets.</p> <p>You will take this medication for as long as your kidney transplant is working.</p>
Monitoring	<p>Your blood work will be monitored for side effects such as low white blood cell counts, red cell counts and/or platelet counts (which may increase the potential for infection or bleeding).</p>
Precautions	<p>Do not open or crush the capsules/tablets. If your skin comes in contact with contents from a capsule/tablet, wash the area with soap and water immediately.</p> <p>You should not take CellCept and Myfortic at the same time. They are not interchangeable.</p> <p>Mycophenolate mofetil may decrease the effectiveness of birth control pills.</p> <p>Mycophenolate mofetil has the potential to harm a developing fetus. This medication must be stopped (by a physician) before attempting to become pregnant. If you are planning to conceive a child, discuss this with your transplant doctor first.</p>
Common side effects	<ul style="list-style-type: none"> <li>▪ lowered resistance to infection</li> <li>▪ nausea, vomiting</li> <li>▪ diarrhea (if you are unable to keep fluids and/or your medication down, go to the Emergency Center at Beaumont for treatment); notify your transplant physician or nurse coordinator if you are having four or more watery stools in a day</li> <li>▪ slow wound healing</li> </ul>

Common side effects <i>continued</i>	Some of these side effects may go away with time or with a dose adjustment by the physician. The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator.
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### **Basiliximab (Simulect)**

Simulect is an intravenous medication that interferes with a specific type of white blood cell that is involved in rejection. Two doses are given while you are in the hospital to help prevent acute rejection. Side effects are very rare, but it is possible to have an allergic reaction to the medicine.

### **Alemtuzumab (Campath)**

Campath is an injectable antirejection medication that is used for patients who meet specific criteria. It is given in place of Simulect (basiliximab). Those patients who are able to receive Campath generally do not require steroid medication (prednisone). The most common side effect is a decrease in white blood cells. Your physician will watch for this at each lab draw.

<b>Antithymocyte globulin (Thymoglobulin)</b>	
Purpose	<p>Some patients need more immunosuppression (anti-rejection medicine) than others. If needed, Thymoglobulin is given intravenously to reduce the number of a certain type of white blood cells (lymphocytes) in your body. This medicine can also be given as treatment for a rejection episode. In this case, you would come to the hospital for four to seven days for treatment.</p>
Common side effects	<p>Fever, chills, joint pains and muscle aches are the most common side effects and may occur with each dose of Thymoglobulin. Because of this, Benadryl and Tylenol are prescribed before each Thymoglobulin dose.</p> <p>A lower white blood count can lead to infection. Your transplant nephrologist will monitor your white blood count and adjust your medicine as needed.</p> <p>You may have an infusion-related allergic reaction such as rash, itching, flushing or difficulty breathing. Tell your nurse or transplant nephrologist if you are allergic to rabbits. If you notice symptoms, Thymoglobulin will be stopped and you will receive medication to help relieve your symptoms.</p> <p>Thymoglobulin interferes with the body's defenses against cancer, which can cause an increased cancer risk. Rarely, a tumor of the lymph glands (lymphoma) may occur. Your transplant nephrologist will be alert to early detection of a tumor.</p> <p>These are only the most common side effects. This is not a complete list of all possible, unusual or rare side effects. If any of these side effects occur, notify your transplant doctor or nurse at your next clinic visit or call the clinic if very bothersome.</p>

## Other medications

Right after your transplant, you will take additional medications which are used to help protect your body from infection. These medications are listed below. You will also be given Omeprazole (Prilosec) to prevent stomach upset and ulcers.

<b>Sulfamethoxazole/trimethoprim or SMX/TMP (Bactrim single strength)</b>	
Purpose	SMX/TMP is an antibiotic. It is used to prevent a specific type of upper respiratory infection (pneumocystis carinii).
Dosing	Take this medication at night with at least 8 ounces of water. SMX/TMP may cause crystals to form in your urine. Water will help to prevent them from forming.  You will take this medication for three to six months after your transplant.
Monitoring	Your labs will be monitored to look for certain possible serious side effects, such as decreased white blood cell count and platelets or kidney dysfunction.
Precautions	Do not take this medication if you are allergic to sulfa medications.  SMX/TMP may cause an allergic reaction. Stop the medication and seek help immediately if you experience a severe skin reaction (rash with hives or severe itching) or other signs of an allergic reaction such as difficulty breathing or swelling in your mouth or throat.
Common side effects	<ul style="list-style-type: none"><li>▪ sensitivity to sunlight</li><li>▪ nausea, vomiting and/or diarrhea</li></ul> <p>The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator.</p>



<b>Valganciclovir (Valcyte)</b>	
Purpose	Valganciclovir is an anti-viral medication that is used to prevent CMV (cytomegalovirus).
Dosing	This medication is usually taken twice a day. You will take this medication for three to six months after your transplant.
Monitoring	Your blood work will be monitored as valganciclovir may cause a decrease in your red or white blood cell counts and/or platelets (which may increase the potential for infection or bleeding).
Precautions	Do not break or crush the tablets. If your skin comes in contact with contents from a tablet, wash the area with soap and water immediately.
Common side effects	<ul style="list-style-type: none"> <li>▪ nausea, vomiting or diarrhea</li> <li>▪ headache</li> <li>▪ change in kidney function</li> <li>▪ decreased white blood cells</li> </ul> <p>Some of these side effects may go away with a dose adjustment by the physician. The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator.</p>

<b>Clotrimazole (Mycelex Troche)</b>	
Purpose	Clotrimazole is a medication used to prevent fungal infections in the mouth. This infection, called thrush, may happen because immunosuppressant medications decrease the “normal” bacteria in the mouth that keep the fungus from overgrowing. Thrush is identified by a white coating on the tongue and inner cheeks.
Dosing	Clotrimazole is a lozenge (or “troche”). Dissolve the lozenge in your mouth. Do not chew or swallow the medicine whole.
Notes	Do not eat or drink anything for 30 minutes after dissolving the lozenge in your mouth. It works by coating the inside of the mouth and throat. This medication is taken for three months after transplant.
Common side effects	<p>Side effects are rare but may include mild nausea, vomiting, diarrhea and/ or stomach pain.</p> <p>The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator.</p>

<b>Omeprazole (Prilosec)</b>	
Purpose	<p>Prednisone may cause stomach irritation and heartburn.</p> <p>Omeprazole helps to prevent stomach and duodenal ulcers by reducing the amount of acid in your stomach.</p>
Dosing	<p>You will be on one or two capsules a day.</p> <p>You will take this medication for at least three months after your transplant.</p>
Common side effects	<p>Side effects are rare but may include abdominal pain, constipation or diarrhea.</p> <p>The above is not a complete list of all possible side effects. Discuss any side effects with your transplant physician and/or your nurse coordinator.</p>

## Chapter 3

### Caring for yourself after surgery

#### Incision care

Clean your incision by showering daily. You may not take a bath or swim until your incision is completely healed. This is usually about six weeks after your surgery. Call your doctor if you notice redness, swelling or drainage from your incision.

Your staples/sutures will be removed in the transplant clinic about two weeks after your surgery.

#### Peritoneal dialysis catheter care

Continue site care as you were instructed before your kidney transplant. Your catheter will be removed one to three months after your transplant. Tell your doctor if there is any redness, swelling or drainage from your exit site.

#### Driving

You may usually begin driving four weeks after your transplant. Seat belts are recommended.

#### Exercise

As you move around more, your strength and endurance should improve. Each person's recovery is different.

For the first month, avoid bending, stretching or lifting more than 10 pounds. Exercise will increase your strength. Exercise is important because prednisone can lead to muscle weakness, especially in the legs. Walking, bike riding and swimming are excellent choices to improve leg muscle strength.

Other benefits of exercise include:

- weight control
- reduced stress
- better digestion
- blood sugar control
- increased energy
- improved sleep
- better glucose

Exercising with weights, jogging and racquetball should only be started after first talking with your nephrologist and/or surgeon.

Avoid:

- contact sports
- horseback riding
- motorcycling
- snowmobiling
- any sport in which you may receive blows or strains to the kidney or abdomen

## **Sexual activity**

After one month, you may resume sexual activities at your own discretion. Noticing changes in your sexual response is common among transplant patients. Changes may be due to the surgical procedure or the disease process, which originally caused your kidney failure. Changes in your medicine could also affect your sexual response. Discuss questions or concerns with your nephrologist. Women of child bearing age should discuss birth control with their nephrologist and/or gynecologist.

## **Pregnancy**

It is safest to wait for one year after your transplant before attempting to become pregnant. A female transplant patient must stop CellCept before attempting to conceive a baby as it may harm the fetus. Discuss your plans with your nephrologist, as he may be able to alter your immunosuppressant medications. During your pregnancy you will be monitored closely by your nephrologist and an obstetrician who specializes in high-risk pregnancy.

## **Return to work/school**

Returning to work and/or school is encouraged. Talk to your nephrologist about resuming these activities.

## **Smoking**

Smoking is a major risk factor for heart disease and certain types of cancer. Therefore, you should not smoke after receiving your transplant. If you need help quitting, consult your transplant nurse or nephrologist.

## **Alcohol**

Alcohol may interact with your medicines. Prograf, Cyclosporine, CellCept and Bactrim are all metabolized by the liver. Combining them with alcohol puts you at risk for harming your liver. We recommend that you limit the amount of alcohol that you drink. Discuss this with your nephrologist.

## **Traveling**

We recommend that you do not travel for the first three months after your transplant while your body heals and adjusts to the new medicines.

Before traveling abroad, consult your nephrologist about vaccinations or preventive medicines you may need.

Be sure to drink only spring or distilled bottled water when traveling outside the United States.

Remember to bring extra medicines with you, in case your trip is extended for any reason. When traveling by plane, store your medicines in your carry-on luggage. Do not put your medicines in bags to be checked onto the plane. Also, protect your medicine from extreme temperatures.

Consider purchasing supplemental health insurance when traveling outside the United States. If there is a change in your kidney function, you may need treatment right away. Think about buying cancellation insurance when ordering airline tickets or making other travel plans.

# Chapter 4

## Diet

Your post-transplant diet should be low in sodium (salt) and saturated fats (low cholesterol). Before discharge, the dietitian will meet with you to discuss your individual diet needs.

Weight gain is common after a kidney transplant. This may be due to several factors. First, food may taste better now that you are feeling better. Second, prednisone may increase your appetite. In order to maintain a healthy weight, it is important to follow the guidelines given to you by your dietitian and to follow an exercise program.

Some general tips:

- avoid fried foods
- limit processed foods- they are high in sodium
- limit your intake of sweets
- choose low fat foods
- eat fiber daily

Drinking at least two to three quarts of fluid per day will help you avoid dehydration. This equals eight to 12 8-ounce glasses of fluid. Water is the best fluid for you to drink.

Some signs of dehydration are:

- decreased weight
- decreased urine output
- increased pulse
- dizziness when standing
- dry mouth and thirst

Some causes of dehydration are:

- not drinking enough fluids
- fever
- vomiting, diarrhea
- diuretics (water pills)

Your medications may cause changes in your calcium, phosphorus, potassium or magnesium levels. Your doctor will monitor your blood levels and let you know if any changes in your diet are necessary.

## Chapter 5

### Monitoring yourself at home

When you are discharged from the hospital, it is your responsibility to update your transplant record book every day. Bring this record and your medication list to each clinic visit. Forms are in the back of this booklet.

#### Things to do each day

- record your temperature each morning and evening in your transplant record book
- record your weight each morning before breakfast
- record your blood pressure each morning and evening
- If you are diabetic, do finger-stick blood sugar (glucose) levels four times a day. Enter the levels into a log. Good glucose (blood sugar) control is essential.
- take medicines as ordered by your doctor
- note any changes, problems or questions to discuss with the transplant doctor or nurse at your next clinic visit

#### When to call the Transplant Clinic

- if weight gain is two to two and a half pounds or greater overnight
- if you notice increased edema (swelling of the ankles, legs or hands)
- if you feel tenderness or soreness over the new kidney
- if your temperature is 100.5 degrees or greater
- if you notice a change in your general sense of well-being (i .e . increased fatigue or decreased energy level)

If diabetic: If your blood sugar levels are consistently above or below the recommended range made by your doctor. An endocrinologist (a physician who specializes in diabetes) will manage your diabetes long-term as the immunosuppressant medication can make your blood sugar levels high.

**Do not hesitate to call the Transplant Clinic during office hours if you have any symptoms of rejection or infection. Prompt treatment is essential. Call the doctor after hours only if you need to receive immediate attention.**

# Chapter 6

## Rejection episode

Rejection is the body's normal response to a new kidney. The body doesn't recognize it as its own tissue and tries to destroy the kidney. However, a rejection episode doesn't necessarily mean you will lose your kidney transplant. You will be given antirejection medicines (immunosuppressants) to lower the possibility of a rejection episode. You will have to take these medications for as long as your transplant is working. If you stop your medications at any time, rejection will occur.

Acute rejection usually occurs within the first six months after a transplant, but it can happen at any time. Rejection is inflammation in response to the "foreign body" (your kidney transplant) that has been placed in your body. Acute rejection usually can be reversed with prompt treatment.

Antibody mediated rejection may occur if your body makes antibodies specific to your donor kidney. There are several treatments available that may reverse this process.

Chronic rejection usually occurs after the first six months. It is different from an acute rejection. It is not reversible by treatment, but the process may be slowed down.

### Signs and symptoms of a rejection episode

- rapid weight gain (more than two pounds in a day or four to five pounds in a week)
- fever of 100.5 degrees or higher
- tenderness or swelling over the new kidney
- flu-like symptoms
- increased blood pressure
- increased creatinine (a measure of kidney function)

You may have some, all or none of these symptoms if you experience rejection.

It can be difficult to decide whether a patient is actually having a rejection episode. An ultrasound of your kidney transplant may be done to rule out other causes of increased creatinine, such as a backup of urine. In most cases when rejection is suspected, a biopsy of the transplanted kidney is done to be sure that the correct treatment is started.



## **Treating rejection**

When an acute rejection episode occurs, it is usually first treated with Solu-Medrol, a form of intravenous Prednisone. Treatment is once a day for three days. It is given as an outpatient in the Infusion Center. Treatment will continue with a “prednisone taper”. You will be placed on a high dose of prednisone pills and the dose will be decreased weekly. You will be given a calendar which will show you how much prednisone to take every day until you are back on your maintenance dose.

If the rejection episode continues, you could be treated with Thymoglobulin or other medications based on your individual circumstance. Some of the treatments require being in the hospital for several days.

## **The importance of taking your anti-rejection (immunosuppressant) medications**

It does not matter how long you have had your transplant. If you stop your immunosuppressant medications, you will have acute rejection.

Order refills as soon as your insurance allows it (usually a week ahead of time). Do not allow yourself to run out of your medication.

If you are having trouble affording your medications, speak with the transplant financial coordinator to see if there may be assistance available to you.

# Chapter 7

## Avoiding infection

The medications you are taking to help your body maintain kidney function and prevent rejection episodes also will lower your resistance to infections.

Some things you can do to protect yourself from infection include:

- For the first month after surgery, avoid crowded areas such as churches, shopping malls, etc.
- Avoid contact with people who are obviously sick. Notify the transplant team if you have been exposed to a contagious disease.
- If you have not had the chickenpox or have not received the chicken pox vaccine, avoid people who have active chickenpox or shingles.
- Use good personal hygiene: Wash your hands frequently and shower daily. (You may take tub baths after your incision has healed completely.)
- Immediately wash cuts and scratches with soap and water and apply antiseptic ointment (such as Neosporin or Bacitracin).
- Have dental check-ups every six months. Before treatment always inform the dentist about your kidney transplant. Antibiotics will be prescribed before dental work is done. This includes having your teeth cleaned.
- Women should have yearly gynecological examinations.
- Avoid cleaning litter boxes, bird cages, or reptile tanks.
- Flu shots are recommended each year.
- Pneumovax shots are given as an initial vaccine with a booster shot five years after the first dose.

## **Signs and symptoms of infection**

- temperature of 101 degrees or higher
- chills
- joint pain
- increased pulse rate (greater than 100 beats per minute)
- swelling
- decreased appetite
- fatigue (lasting for more than one or two days)
- headache
- stiff neck
- swelling or drainage anywhere the skin is broken
- burning sensation when urinating
- sore throat and/or cough
- nausea, vomiting and diarrhea
- cloudy urine
- a rash or other skin change

Should one or more signs or symptoms occur, notify your nephrologist or nurse immediately.

## **Treatment of infection**

Many infections can be treated and cured at home with prompt and proper use of antibiotics. Severe infections may require hospitalization.

It is important to know that antibiotics do not work against viral infections, such as colds. If you have cold symptoms, ask your nephrologist or nurse for a list of over-the-counter symptom relief medications that you may take safely.

## **Cytomegalovirus (CMV)**

Cytomegalovirus infects most of us at some time in our lives. Because it has some of the same symptoms as a flu virus, most people do not even realize that they have been infected. However, in immunosuppressed patients, CMV can be a serious complication. For this reason, we check your blood for antibodies to the virus before transplant. If you already have antibodies, it is unlikely, though possible, that the virus would be reactivated. If you do not have any antibodies, and you receive a transplant from someone who does, it is possible to become infected with the virus from the donor's kidney. There is a preventive medication available, which can give you protection against activation of the virus. You will be notified if you need this medicine.

## **Food safety**

The following are just a few important food safety tips. The transplant dietitian will provide additional information.

### **At home**

- Wash hands and kitchen surfaces frequently while preparing food.
- Don't use the same utensils or plates for cooked foods that were used to prepare raw foods such as meat, fish or eggs.
- Use a food thermometer to make sure that foods are cooked to the correct temperature (refer to [www.fda.gov](http://www.fda.gov) for guidelines).
- Refrigerate foods within one hour of cooking.
- Check "use by" dates.
- Do not drink unpasteurized products (e.g. apple cider)
- Do not eat raw meat or seafood.
- Wash fruits and vegetables before eating them.

### **Dining out**

- Avoid buffets and salad bars.
- Sprouts (bean, alfalfa and others) are frequently contaminated. They are often used in wraps, so ask before ordering.
- Avoid eating eggs that have yolks that are not fully cooked.
- Order meat "medium" or "well done."

# Chapter 8

## Immunizations/vaccinations

An important thing to remember is that transplant patients should never receive a “live” vaccine.

Examples of “live” vaccines are:

- **Oral polio vaccine**

Avoid contact with anyone who has received the oral polio vaccine for six weeks following the vaccination. It is possible to develop polio if exposed to any body fluids of the vaccinated person. The injectable form of the vaccine is not a “live” vaccine, and is safe for transplant patients.

- **MMR (measles, mumps, rubella)**

Transplant patients should not receive this vaccination, but there is no apparent risk if family members receive the vaccine.

- **Chickenpox/Shingles**

Transplant patients should not receive these vaccinations, but there is no apparent risk if family members receive the vaccine. Notify your doctor immediately if you have been exposed to chickenpox.

- **Rotavirus vaccine**

Avoid contact with anyone who has received the rotavirus vaccine for six weeks following the vaccination. It is possible to develop rotavirus if exposed to any body fluids of the vaccinated person.

<b>Vaccinations safe for transplant patients</b>	
Influenza	recommended yearly in the fall
Pneumovax	given as an initial vaccine followed by a booster shot five years after the first dose
Tetanus and diphtheria	Booster shots are recommended every 10 years. If you are injured with a dirty object, a booster is recommended after five years.

# Chapter 9

## Cancer precautions

The immunosuppressants you will be taking to prevent rejection of your kidney transplant increase your chances of developing some forms of cancer.

We try to use the least amount of anti-rejection medication to best suit your individual needs to avoid some of these potential problems. Close monitoring of the dosages of anti-rejection medications is important.

### Skin cancer

The most common cancer seen in patients after transplant is skin cancer. Skin cancer is caused by being in the sun for too long or over too many years. More than 90 percent of all skin cancers are on parts of the body exposed to the sun. The face, neck, ears, forearms and hands are the most common locations of skin cancers.

When diagnosed and treated promptly, this type of skin cancer has a high cure rate. If untreated, skin cancers enlarge, but rarely lead to severe illness or death.

It is recommended that you visit a dermatologist to assess your risk for developing skin cancer.

### Look for these signs of skin cancer

- Any new, small, shiny or fleshy nodules on exposed skin could be an early warning of a basal cell skin cancer.
- Squamous cell carcinoma usually starts as a red, scaly, flat patch or a nodule.
- Any sore that bleeds or doesn't heal rapidly should be brought to your doctor's attention.

### Take precautions to decrease the risk of skin cancers

- When outside, always apply sunscreen to all exposed body areas one hour before sun exposure. Reapply the sunscreen generously every two hours while in the sun. Sunscreens labeled with an SPF (sun protection factor) of 30 or greater provide the best protection.
- Limit outdoor activities between 10 a.m. and 2 p.m. in the summer months (11 a.m. and 3 p.m. daylight saving time). Play golf, tennis or swim in early morning or late afternoon.

- Wear light protective clothing to add protection to the back, shoulders, arms, chest and legs. Wear a wide brimmed hat to protect the face.
- Stay in the shade as much as possible.
- Avoid overexposure to the harmful rays of the sun on cloudy days. You still may become sunburned when the sky is full of clouds.
- Some drugs and cosmetics may increase the possibility of sunburn. Your doctor or pharmacist can advise you about medications that can cause problems in the sun.
- Avoid tanning booths. Tanning booths add more damage to what is received from natural sunlight. Tanning booth bulbs give off ultraviolet light and can cause sunburn, skin cancer and premature skin aging. A tan can give some protection against sunburn, but skin damage continues even with a tan.

### **Other cancers**

People with transplants may have other types of cancers at a slightly higher rate than the general population. Promptly report any unusual bumps or lumps on your body to make an early diagnosis of a tumor.

All female transplant patients should keep regular appointments (every year) with their gynecologist. They also should perform a monthly self-breast exam to monitor for lumps. Ask your nurse if you are unsure how to perform a self-breast exam.

Your doctor also may recommend other cancer screening tests such as a colonoscopy or prostate exam (for men over 50) or a mammogram (for women over 40). This will be determined by your age and risk factors.

# Chapter 10

## Personal and financial concerns

A new kidney is the start of a new life. Significant improvement in health and quality of life often follow a kidney transplant. However, the traumatic effects of anesthesia, surgery and steroid treatment may result in a variety of responses. These can include anxiety, confusion and irritability (particularly when steroids are at their highest level). These emotional responses vary in how often they occur, how long they last and how intense they are.

A transplant social worker is available and encourages all transplant patients and family members to discuss:

- emotional responses to the transplant
- adapting to changes in your body
- psychological acceptance of a body part from another individual
- coping with the uncertainties of the transplant experience
- developing strategies and resources for re-entry into roles within and outside the family
- vocational rehabilitation
- networking with other transplant patients and families
- anonymous correspondence with the donor family

Your social worker or financial representative can meet with you to discuss Medicare and other insurance issues. Many of the medicines/treatments that you are receiving are very expensive.

You will need to ask your insurance carrier about the following:

- prescription coverage
- co-pays/deductibles for office visits
- coverage for lab work and other tests

The current Medicare coverage for immunosuppressant medicines is 80 percent of the cost. If you have this Medicare coverage, you need to plan ahead so you will be able to pay for these medicines once the coverage period is over.

Report any expected health insurance and or family concerns to your social worker or financial representative as early as possible in order to minimize problems. Please refer to "The Financial Handbook for Renal Transplant Patients" for more information.



## Organizations for information and support

### **National Kidney Foundation of Michigan**

1169 Oak Valley Dr. ▪ Ann Arbor, MI 48108

800-482-1455 or 734-222-9800

[www.nkfm.org](http://www.nkfm.org)

*Provides patient newsletters, educational materials and assistance in obtaining medicines. Opportunities to participate in fundraising activities.*

### **American Association of Kidney Patients**

14440 Bruce B. Downs Blvd. ▪ Tampa, FL 33613

800-749-2257

*A leader for patient-centered education. Provides tools to track health information. Active voice in public policy regarding patients with kidney disease.*

### **American Kidney Fund**

11921 Rockville Pike, Suite 300 ▪ Rockville, MD 20852

800-638-8299 ▪ Patient grants: 800-795-3226

[www.kidneyfund.org](http://www.kidneyfund.org)

*Has limited grants to help cover the cost of medicines, transportation, etc. Has a growing advocacy network.*

### **Michigan Rehabilitation Services**

[www.michigan.gov/mdhhs](http://www.michigan.gov/mdhhs)

*Can assist with job training and job placement for disabled patients.*

*There are several local offices. Check the website for the closest one.*

### **Transplant Recipients International Organization (TRIO)**

13705 Currant Loop ▪ Gainesville, VA 20155-3031

800-TRIO-386

[www.trioweb.org](http://www.trioweb.org)

*Provides newsletters, education and a support network. Promotes donor awareness.*

### **Transplant Living**

[www.transplantliving.org](http://www.transplantliving.org)

*A project of the United Network for Organ Sharing (UNOS). Offers patient resources and educational materials.*

Some pharmaceutical companies sponsor programs that help patients who cannot afford their medicines. Contact the transplant financial representative if you are having difficulty paying for your medicines.

# Chapter 11

## Clinic visits

### Outpatient follow-up care

You will be closely monitored by the transplant physicians and nurses in the Transplant Clinic in the Beaumont Medical Office Building (Royal Oak) for at least three months after you are discharged from the hospital after your transplant.

At first, you will be scheduled for a physical exam and blood tests twice a week. The number of times you visit will decrease over the next several months. During this phase of your post-transplant care, your immunosuppressant (anti-rejection) medicines will be adjusted and your kidney's function closely monitored. You may need to come to the clinic more or less often, depending on the results of your blood tests/condition.

### Follow these steps when visiting the Transplant Clinic

- Register with the receptionist.
- A post-transplant nurse coordinator will assess you. You will be weighed, your vital signs will be checked and you will be asked for a list of your medicines (including any vitamins or supplements that you are taking). The nurse coordinator will review your records from home (blood pressure, weight, etc.) and answer many of your questions.
- The transplant nephrologist will examine you and tell you about any changes that need to be made in your medicine or care. The nephrologist will answer any other questions you may have about your progress.
- After you see the nephrologist, check out at the front desk. Before leaving, make an appointment for your next visit.
- The office staff will let you know when and where to have your blood drawn. Routine tests include CBC, creatinine and BUN, and Prograf levels. Blood glucose (sugar) and other tests will be done as indicated by your nephrologist.
- You will be asked to provide a "clean-catch" urine sample. If you are unfamiliar with this procedure, the office staff will instruct you.

## **Remember**

- Do not take your morning Prograf or CellCept dose on the days of doctor appointments/lab visits. Bring your Prograf and CellCept to the office so you can take it after your blood is drawn.
- You will be referred back to your personal nephrologist for continued medical follow-up when your kidney function is stable. That may be anywhere between three months and one year after your transplant. At that point, your primary nephrologist will be responsible for caring for you and your transplant. Call their office for questions, problems or medicine refills.
- Establish yourself with a primary care physician (“family doctor”) for common problems such as colds or flu or sprains.

## **Long term follow-up care for renal transplant patients**

- Monthly lab work, including CBC, BUN, creatinine and Prograf (tacrolimus) level
- Office visits every one to three months depending on the stability of your condition and the length of time since your transplant (This is determined by your primary nephrologist.)

# Chapter 12

## Normal lab values

Right after your transplant surgery, you will have blood drawn twice weekly. Eventually you will have your labs checked monthly for as long as your transplant is functioning. We will call you if any of your labs are of concern. If you wish to know your lab results, please call after 2 p.m. the day after you have your labs drawn, or you may get a copy of your lab results at your next clinic visit.

We encourage you to sign up for *myBeaumontChart*. It provides you with access to your lab and test results, your medication list and more.

### Some of the labs we monitor

(These “normal” levels are only guidelines, based on Beaumont’s lab ranges as of July 2016.)

Lab	Normal value
Creatinine (measures kidney function)	0.6-1.4 mg/dL
BUN (measures kidney function)	8-22 mg/dL
Potassium	3.5-5.2 mmol/L
Phosphorus	2.3-4.3 mg/dL
Hemoglobin	13.5-17 g/dL
Hematocrit	40.1-50.1%
White blood count	3.5-10.1 bil/L
Platelets	150-400 bil/L

Factors which could cause an increase in creatinine:

- dehydration
- rejection
- lab variance
- infection
- obstruction
- high levels of Prograf
- low levels of Prograf (missing doses of your immunosuppressants can cause rejection)

Factors which could cause an increase in BUN:

- dehydration
- rejection
- increased protein intake

While your labs may not always be in the “normal” range, they may be acceptable. As our team looks at the patient as a whole, every patient’s “normal” range is different.

# Chapter 13

## Definitions

### Acute rejection

Acute rejection can happen at any time after a kidney transplant. During an acute rejection episode, the creatinine rises. This usually can be treated by taking higher doses of immunosuppressive (antirejection) medicines until the creatinine returns to a baseline.

### Acute tubular necrosis (ATN)

ATN is reversible kidney damage resulting in delayed kidney function. It can be caused by medicines or injury during organ storage.

### Antibody

An antibody is part of the immune system that helps the body fight infections and foreign substances.

### Antigen

An antigen is the “marker” that stimulates the body to produce antibodies.

### Anti-rejection medicine

This medicine helps prevent your immune system from struggling against and rejecting the new kidney. Also known as immunosuppressive medicine.

### Biopsy

A diagnostic test in which a small needle is inserted into the kidney and tissue is removed for analysis. The tissue can show rejection, disease or toxicity from medicines.

### Bladder

The part of the urinary tract that receives urine from the kidneys and stores it until you urinate.

### Blood typing

A blood test that indicates blood group. You can be O, A, B or AB. The recipient's blood type needs to be compatible with the donor's blood type to receive the kidney transplant.

## **BUN**

BUN stands for blood urea nitrogen, a waste product from the kidney after your body has broken down protein.

## **Chronic rejection**

Chronic rejection is a process that may happen after a kidney transplant. It can develop over months or even years. During this process, the creatinine slowly rises. There is no medicine that reverses chronic rejection, but there are some that may slow it down.

## **Chronic renal failure**

Chronic renal failure is permanent damage to both kidneys that cannot be corrected. It is treated by dialysis or a transplant.

## **Creatinine**

Creatinine is a waste product of muscle metabolism. Creatinine level serves as a good indicator of kidney function.

## **Cross matching**

Cross matching is a test to find out if the blood of the kidney donor and the person receiving the kidney are compatible.

## **Deceased donor**

A deceased donor is a person who has died of causes that should not affect future kidney function. They or their family have generously offered organs and/or tissues to be transplanted.

## **Diastolic**

This is the bottom blood pressure number. It shows the force of the heart muscle at rest. This is when the heart expands and fills with blood.

## **Glucose**

Glucose is a type of sugar found in the blood.

## **Graft**

Graft is another name for your “new” kidney.

## **Hypertension**

Hypertension is another word for high blood pressure.

## **Immunosuppressive medicine**

The drugs that helps prevent your immune system from struggling against and rejecting the new kidney. Also known as anti-rejection medicine.

## **Intravenous (IV)**

Into or within a vein. It also refers to fluids and medicines that are injected into a vein through a needle or catheter.

## **Kidney**

One of the two bean-shaped organs located beside the spine, just above the waist. They remove waste and balance fluids in the body by producing urine.

## **Nephrectomy**

Surgically removing one or both kidneys.

## **Rejection**

The way your body responds to a “foreign object,” such as a new kidney, is rejection. Rejection can be acute or chronic (see definitions: acute rejection and chronic rejection).

## **Renal**

Renal means having to do with the kidney.

## **Renal ultrasound**

This is a test that uses sound waves to look at the kidney.

## **Systolic**

Systolic is the top blood pressure number. It measures the force of the heart muscle as blood is pumped out of the heart chambers (contractions).

## **Tissue typing**

This is a blood test that evaluates if there is a tissue match between organ donor and recipient. It is done before a transplant.

## **Transplant**

Transplant is transferring organs or tissues from a donor to a recipient.

## **Ureters**

Ureters are two tubes that carry urine from the kidney to the bladder.

## **Urethra**

Urethra is the tube from the bladder that allows urine to flow out of the body.

## **Urinary tract**

This system is made up of the kidneys, ureters, bladder and urethra. It produces, moves, stores and eliminates urine.

Adapted from "Living with Kidney Transplantation" by Sand



# Patient record

Week of \_\_\_\_\_

	Mon	Tues	Wed	Thur	Fri	Sat	Sun
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Temp before dinner							
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Things to mention to my transplant team:

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24 hour urine output							

Things to mention to my transplant team:

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**Each person is an individual  
and responses may vary.  
If you have any questions,  
please talk to a member of  
your health care team.**

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Royal Oak, Michigan 48073-6769  
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TDD: 248-898-1986

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