



TEXAS TRANSPLANT INSTITUTE

A member of the Methodist Healthcare System

www.TexasTransplant.org

Pre-Transplant Clinic Education Manual

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Welcome

Welcome to the Texas Transplant Institute on the campus of Methodist Specialty and Transplant Hospital. Since the beginning of our transplant program in 1984, we have been dedicated to providing the highest quality care to our patients; their families, as well as other health care providers. Our Transplant Team, which includes our physicians and staff along with our patients, their physicians and their families, has developed a program to provide continual care before, during, and after transplantation. Our team approach has allowed us to give individualized attention to insure patient and donor comfort, satisfaction, and the best possible outcome of transplantation.

We dedicate our services at the Texas Transplant Institute to our organ donors and donor families for their generous gift. We will strive to maintain our goal of taking the best possible care of every gift entrusted to our patients and us.

This notebook is for you to help you learn about transplant so that you may have a choice for treatment of your kidney disease. If you have any questions or concerns, please feel free to ask any of the transplant team. We will always do our best to help you to make the decision that is best for you.

Your Transplant Team

I. Transplant Coordinators

Three groups of nurses will assist you and your family during the transplant process. These nurses and an organ perfusionist are on call 24 hours a day, seven days a week.

A. Pre-Transplant Coordinator:

1. Involved in screening and educating you as the patient during your evaluation and will work with your doctors/dialysis center to prepare you for your transplant.

B. In-Patient Coordinator:

1. Involved in your care while you are hospitalized for your transplant.
2. Will educate you on how to care for yourself after your Transplant.
3. Will make your arrangements for care after transplantation.

C. Post Transplant Coordinator:

1. Will see you in clinic for your follow-up visit after your transplant.
2. Will work with your kidney doctor in your care after transplantation.

II. Social Workers

- a. Will help you with your emotional concerns before and after transplantation.
- b. Will help you plan for the day to day and long term needs such as how and where to get your medicines
- c. Will help explain some of the financial issues of having a transplant.

III. Dietitian

- a. Will evaluate your nutritional status before your transplant.
- b. Will educate and assist you with your nutritional needs before your transplant, while you are in the hospital and after your transplant.

IV. Secretaries/Support Personnel/Data Coordinators

- a. Will schedule your evaluation and follow-up appointments.
- b. Will direct you to the appropriate area during your clinic visits.
- c. Will answer questions you may have or refer you to the appropriate personnel to answer your question
- d. Will draw your blood for tests that will be needed
- e. Will help schedule your surgery and fill out the appropriate forms that are needed before and after your transplant.
- f. Will collect and maintain data on each patient for research purposes and federal regulations.

V. Financial Coordinator

- a. Will evaluate your financial resources before and after transplant.
- b. Will research benefits and eligibility of your insurance.
- c. Will coordinate benefits when more than one insurance is available.
- d. Will work with you to make a financial plan for your transplant.

VI. Case Manager

- a. Works with Transplant team to ensure all aspects of care are met during your hospitalization.
- b. Works with the transplant coordinators to make sure your medications are ready for you upon discharge from the hospital.

Types of Kidney Transplants

A transplant is an operation in which a kidney from one person is put into another person whose kidneys have almost or completely stopped working. If the kidney works well, the patient will have less food and fluid restrictions, feel much better overall, and return to an almost normal life. This is the goal of transplantation.

There are two types of kidney transplants:

1. Living donor transplant
2. Cadaver donor transplant

These types of transplants are described in the sections to follow. With either type of these transplants, your blood is tested so that we can match you with a proper donor. These tests are:

1. Blood type: This will tell you if you are an “A”, “O”, “B”, or “AB” type. We do not check for the Rh factor, which shows whether you are positive or negative.
2. Tissue typing: This is the DNA or genetic testing.
3. Antibody testing: This checks the level of the antibodies in your blood. Antibodies protect your body from something that does not belong in your body. The higher level you have, the harder your body fights off things that do not belong there. This can make it harder to find an organ for you.

You may also need more tests such as XRAYs or an EKG. The transplant team will also check you medically, psychosocially, and financially to make sure everything is fine before adding you to the list or proceeding with a live donor transplant.

Remember: You must first be cleared for transplant before you can be added to the list or have a live donor transplant.

Living Donor Transplant

A living donor transplant is when a healthy, living person donates to someone who needs a transplant. People who can donate must be 18 years old or less than 70 years old. They must be in excellent health and must pass all tests done by the transplant team. If any part of the tests come back as unacceptable, then another donor must be considered. If there is no other donor, then the recipient can be placed on a waiting list.

People that can be considered for donors can be blood relatives or someone who has an emotional bond with you such as a husband, wife, or good friend.

Living transplants are the ideal choice for various reasons:

- Higher success rates
- Better matching (blood relatives only)
- More convenient scheduling of surgery
- Less medications needed

Cadaveric Donor Transplant

A cadaver donor transplant is when someone has died and donated their organs to someone who is on a waiting list. Once someone has been placed on the list, they will have to wait until an organ becomes available and is assigned to them. This can be at any time of the day, any day of the year so you must be ready to come to the hospital when called.

The wait time will be different from one person to another because of different reasons. One reason is that the government has made rules so that organs are given out fairly. A point system is used in order to select a recipient. These points are a total of five different areas that are:

- Age
- Length of time on the list
- How well the donor and recipient match genetically
- Antibody level
- Medical urgency

The people with the most points that will be at the top of the list with one donor may not be at the top of the list with another donor because their points may be different with this donor. This donor may not match as well or someone who has waited longer may come up first.

Another reason that one person may wait longer than another may be because of the blood type. Different blood types have different wait times. The average wait time for the following blood types is as follows:

- “A” blood type: 1 to 1 ½ years
- “B” blood type: 2 1/2 to 3 years
- “O” blood type: 2 to 2 1/2 years
- “AB” blood type: About 1 year

Everyone is placed on a local and national list so that if a perfect matched kidney from another Transplant Center becomes available for someone on our list, they must offer it to us. We will then check to see if our patient is medically stable and then accept the kidney or refuse it. Being on the national list will give you a chance to get a perfect matched kidney, but may not make it any sooner for you to receive a kidney.

It is very important to stay healthy and keep us updated with any changes such as new phone numbers, new address, or new insurance information. Everyone who is on the list will also need to be checked again every year by the transplant team.

Be prepared at all times to come to the hospital!

BEFORE SURGERY

If you are to receive a kidney from a living donor, you and your donor will come to the clinic one day before surgery. All the pre-operative tests will be done at this time as well as the pre-surgery education. The medication to keep you from rejecting the new kidney (immunosuppressive medicines) will be started that day. Both of you will only be able to have a clear, liquid diet that evening and nothing to eat or drink after midnight. The surgeons for you and your donor will see you in clinic that day. Your nephrologist will also see you and make sure you are prepared for the transplant. Once everything is completed, then both of you will go to a hotel near the hospital.

The morning of the surgery, you and your donor will be brought to the day surgery area by the hotel shuttle. The donor will be taken to the operating room an hour before you will be taken. The surgeries will occur in rooms side by side and will end close to the same time.

If you are to receive a kidney from a cadaver donor, it is very important for the transplant team to be able to reach you at all times. During the waiting time:

- Try to stay as healthy as possible
- Take your medicines as ordered
- Follow your fluid and diet restrictions
- Do not miss any dialysis treatments
- Notify the transplant center of any changes in address, phone numbers or insurance
- Notify the transplant center of any trips and where you can be reached.

When you are called, the transplant nurse will ask you how you are doing medically. If you have a cold, sore throat, fever, any type of infection, or are recovering from these, you must let the nurse know. It would be better to wait for another kidney, than to risk giving you a serious infection. You will be given instructions on what to do next such as:

- When to come to the hospital
- Where to come
- Food and fluid restrictions
- What to bring

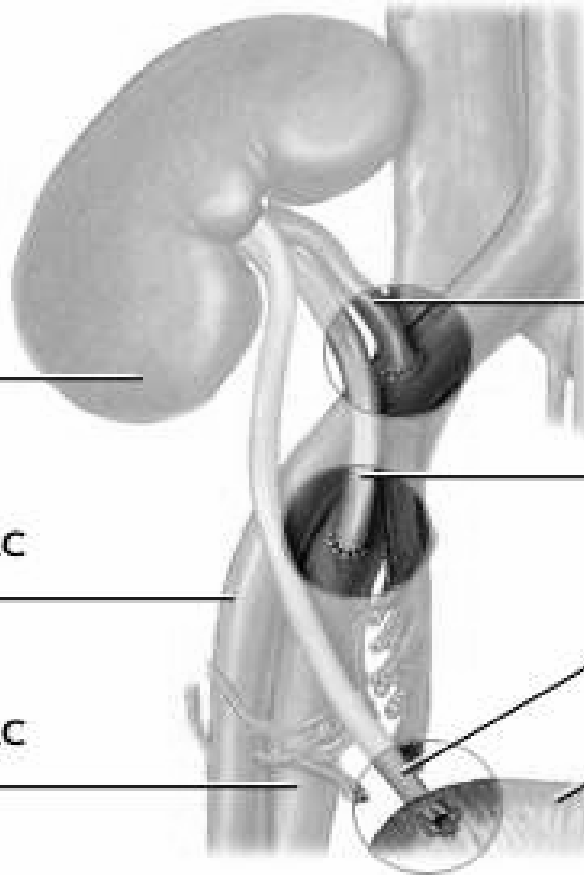
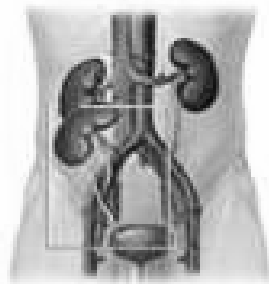
Come to the hospital as soon as possible, but do not panic and drive carefully. It is better for someone to drive you to the hospital because you cannot drive home when you are discharged. If you need to have dialysis before surgery, this will be done at the hospital. You will also have a complete examination by the doctor which will include blood tests and x-rays. Once you have had everything done and cleared by the transplant doctors, you will go to surgery.

*** Whether you will be receiving a Live Donor or Cadaver Transplant it is important that the patient(s) stop smoking. Smoking cessation programs are available and your doctor can assist you in making the best choice for your situation. The operation may be cancelled if you have not stopped smoking prior to your surgery.**

*** If you have a Living Donor, he or she must stop smoking at least two weeks prior to their surgery to prevent any potential complications (related to smoking) during their surgery. The operation may be cancelled if the live donor has not stopped smoking prior to their surgery.**

THE OPERATION

The operation is usually about four hours long. An incision will be made in the lower half of the front of the abdomen on either the right or left side. This is not where your kidneys are located, so they will not be disturbed. Your new kidney will be connected to your own blood vessels and your bladder. A tube will be placed in your bladder after you are asleep in the operating room. This is used to drain your urine and keep your bladder empty so that it can heal. This tube (Foley catheter) will stay in for 4-5 days. An IV will be placed in your arm and neck after you are asleep. These may remain there for a few days until you can eat or until all the medicines are given. The doctors will inform your family when the operation is over and you will be transferred to the intensive care unit (ICU). You will stay here a day or two until you are stable and ready to move to the transplant unit.



Donor kidney

Renal artery

Renal vein

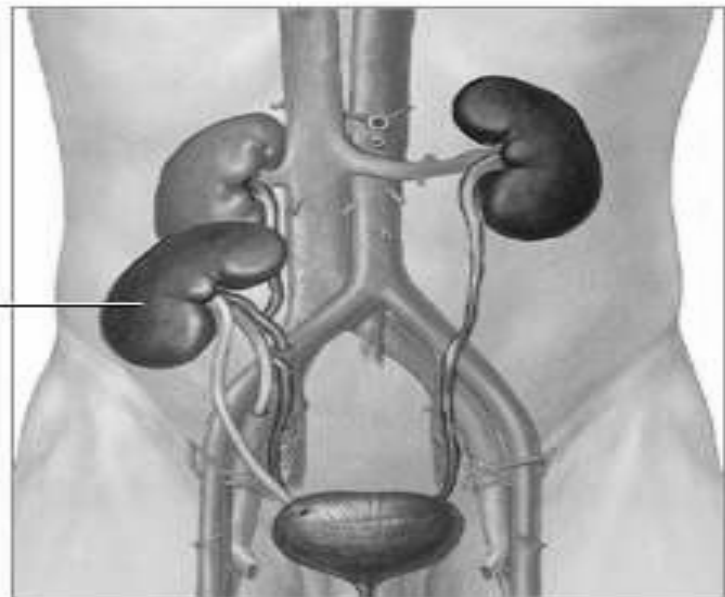
Right iliac artery

Ureter

Right iliac vein

Bladder

Transplanted kidney



AFTER THE OPERATION

Once you are in the ICU, you will be monitored very closely for a day or two. A nurse will check you every hour to make sure your kidney is working and that you are not having any complications. Blood will be drawn to see how the kidney is working and to make sure you are not having any problems. The nurse will also measure how much fluid you take in and how much urine you are putting out. Your blood pressure, pulse and temperature will be monitored every hour until you are stable. The next day you will be moved to the transplant unit if everything is normal. At the transplant unit, you will be closely monitored for possible complications such as:

- Urine leaks
- Lymphoceles
- Failure of the transplant to function
- Infection
- Rejection

The usual hospital stay is 5-7 days for you. The donor usually stays 3-4 days.

Delayed Graft Function

Delayed Graft Function is a condition that may happen right after having a kidney transplant operation. This condition is when the kidney does not start working right away and may need dialysis for a few days or even a few weeks. The transplant doctors will give you new medications to help the new kidney to start working. Once the kidney starts to work, the creatinine level starts to go down and the urine output increases. ATN, or delayed graft function, is not uncommon and does not mean that your kidney will not work.

REJECTION

Once you have received a kidney, there is a possibility that you will have a rejection episode. This does not mean that you have lost your kidney. It means your body has realized that your new kidney was not a part of your body and it is trying to fight it off, like your body does with an infection. It is not uncommon to have a rejection episode within the first few weeks after your transplant.

The following are signs and symptoms of rejection that need to be reported to your doctor immediately:

- INCREASED CREATININE (BLOOD WORK THAT TELLS YOU HOW WELL THE KIDNEY IS CLEANING THE BLOOD. TO SEE THIS, YOU MUST HAVE LABS DRAWN AS ORDERED)
- DECREASED URINE OUTPUT
- SUDDEN INCREASE IN WEIGHT
- INCREASE IN BLOOD PRESSURE
- SWELLING TO HANDS AND FEET
- INCREASE TEMPERATURE
- FLU-LIKE SYMPTOMS
- SWELLING OR TENDERNESS TO NEW KIDNEY

To treat the rejection, you will be given medication through a vein or by mouth, depending on how strong the rejection is. Even if you do everything the doctor recommends and you take all your medicines, you may still have a rejection episode. Early detection is very important and also why you must not miss any appointments. The transplant team can treat and usually reverse rejection when treated early.

Medications

All patients who receive a transplant will be on immunosuppressive medication for the life of the kidney. These medications lower a person's ability to fight off foreign objects so that the body would be less likely to reject the kidney. Each person reacts differently to the medications, so each person will have different medicines, doses, or combinations of these medicines.

Along with these new medicines, there will be a few more medicines that will be given for a short time only. These medicines are given to prevent some of the side effects of the immunosuppressive medications.

- **Bactrim:** prevents certain pneumonias
- **Cytovene/Acyclovir:** prevents some viral infections
- **Mycelex:** prevents fungal mouth infections
- **Pepcid:** prevents stomach ulcers
- **Surfak:** prevents constipation

Some individuals may also need blood pressure medications and or medications that remove extra fluid in the body. The medications are given according to each recipient's needs and the dose or drug may change. Medication classes are given while you are in the hospital for your transplant and you will be responsible for knowing which medicines you are receiving.

The recipient will not go home until he or she knows the name, dose, action and side effects of all their medicines.

The medications are the most important part of a transplant and you must know all about them in order to take care of yourself and your new kidney. The following pages list all the immunosuppressive medications that we give to patients. Each patient will be given a combination of some of these. Please review them so that you are aware of what they are and what side effects they may have.

Remember: You will have to know all about the medicines for your kidney.

Steroids

(Deltasone/Prednisone)

Purpose: Antirejection

Dose: Twice a day at first, then once daily

Side Effects:

- Increases risk of infection
- Weakens bones, especially at joints
- Increases appetite
- Makes cheeks puffy
- Weight gain (usually in the midsection of the body)
- Diabetes
- Acne on face, chest and back
- Hair growth on body
- Skin sensitivity to sun
- Cataracts/Glaucoma
- Stomach irritation or ulcers
- High blood pressure
- Emotional mood swings
- Bruising and thin skin
- Muscle weakness, especially in legs

Most of these side effects will decrease or disappear when dose is lowered.

Prograf

Purpose: Anti-rejection

Dose: Twice a day

Side Effects:

- ***Increase risk of infection***
- Increase risk of cancer and tumors
- Increased creatinine, possible toxicity to the kidney
- High blood pressure
- Nausea, vomiting, or diarrhea
- Elevation of blood tests of the liver
- Elevated blood sugars-can cause Diabetes and may require Insulin to control sugars
- Headaches
- Rash
- Hand tremors
- Blurred vision
- Difficulty sleeping and/or nightmares
- Burning or tingling of hands or feet

Cellcept

Purpose: Anti rejection

Dose: Twice a day

Side Effects:

- Increased risk of infection
- Nausea, vomiting or diarrhea
- Anemia
- Over-tiredness
- Mouth sores
- Occasional hair loss

Neoral

Purpose: Anti-rejection

Dose: Twice a day

Side Effects:

- Increased risk of infection
- Increased risk of cancer or tumors
- Increased creatinine, possible toxicity to the kidney
- High blood pressure
- Increased hair growth on face, trunk, arms, legs
- Hand tremors
- Seizures
- Growth of gums over teeth
- Increase in liver function tests

Rapamune

Purpose: Anti-rejection

Dose: twice a day

Side effects:

- Increased risk of infection
- High cholesterol/triglycerides
- High blood pressure
- Rash
- Acne
- Anemia
- Over tiredness
- Joint pain
- Diarrhea
- Low potassium

TRANSPLANT NUTRITION

Diet is one of the most important parts in keeping your body healthy. Diet becomes even more important when you have kidney failure. You must be careful about what you eat. Because your kidneys can not get rid of waste products, certain foods must be limited or avoided. At the same time, your body needs nutrients to stay healthy. Your dialysis dietitian will continue to teach you how to stay on a kidney diet.

As part of your evaluation to receive a kidney transplant your nutritional status will be checked for the following:

- Malnutrition – weight loss, low proteins
- Obesity – especially in the lower part of the belly
- How well you follow your diet – lab values, fluid gains

If you are found to have one of the above problems, it will need to be fixed before you receive a transplant. Your dialysis dietitian will be able to help you. The following pages can be helpful in keeping your labs and fluids within the ranges set by your clinic.

DIET AFTER A TRANSPLANT

After a kidney transplant the diet will change. It will become more normal. You will no longer be restricted in

- **Phosphorus**
- **Potassium**
- **Fluids**

You may still need to follow a certain diet depending on your medical history. A healthy diet can be useful in keeping you healthy. Because of a working kidney and the new medicines you will be on, you will be followed for:

- **Anemia**
- **Weight gain**
- **Diabetes**
- **Heart disease.**

Anemia is when you do not have enough red blood cells. Kidneys help with the making of red blood cells. When your kidneys do not work or do not work well, you may become anemic. After a transplant your anemia should get better. The color in your face will return and you may notice an increase in your energy level. Some people will also need a vitamin to help their anemia get better.

Weight gain after a transplant is common. After a transplant your taste buds and appetite will return. Most people return to their normal adult weight. (The weight they were before having kidney disease.) A transplant dietitian will watch your weight. If too much weight is gained, you will be placed on a low calorie diet.

Some people after a transplant will get diabetes. Some of the medicines can cause the blood sugars to become high. If this happens, the patient will be placed on a diabetic diet to help control blood sugars. The patient may also need insulin (an injection) to help bring the blood sugars into the normal range. If this happens, a diabetes nurse will teach you how to take care of your diabetes.

Kidney transplant patients are at high risk for heart disease. As part of the follow up after a transplant you will be checked for risk factors. Some of the risk factors are smoking, cholesterol levels, diabetes, obesity, high blood pressure, inactivity and a family history of heart disease. By lowering the number of risk factors you can lower the risk of heart disease.

FLUIDS AND WEIGHT GAINS

When the kidneys no longer work or work well you will need to decrease your fluids or they will build up in the body. Fluids are any items that will melt at room or body temperature. Fluids must be measured carefully. Fluid weight builds up quickly. Fat or muscle weight gain will build up more slowly.

High fluid gains between dialysis treatments can lead to:

- Swelling
- High blood pressure
- Shortness of breath
- Heart failure.

When large amounts of fluid are “taken off” during dialysis you may have:

- Muscle cramping
- Low blood pressure
- Nausea
- Dizziness

If you bring less fluid weight to dialysis, your treatment can be easier. One pound or half a kilogram is equal to 2 cups of fluid. Your doctor and dietitian will tell you how much weight or fluids you can bring to dialysis. If someone always brings in too much fluid, the damage to his or her heart can not be fixed.

HELPFUL HINTS FOR CONTROLLING FLUID GAINS

- Drink only when thirsty.
- Keep your blood sugar in the normal range. High blood sugars will make you thirsty.
- Try eating ice cold or frozen fruits, vegetables or fluids (example: berries, grapes, flavored drinks).
- Try eating hard candies, chewing gum or sliced lemon wedges to wet your mouth.
- Most people find ice more satisfying than the same amount of water, since it stays in the mouth longer. Remember ice still counts as fluid.
- Staying busy may help you forget about wanting fluids.
- Know how much fluid your cups and glasses hold. Try marking your glass with stripes to know how much fluid you are drinking.
- Avoid high sodium foods. Some high sodium foods are listed below

Salt	Regular Canned Vegetables	Salted
Popcorn		
Seasoned salt	Sauerkraut	Crackers
Garlic or Onion Salt	Pickles, Olives	Salted Nuts
Lemon Pepper	Regular Canned Soup	Salted Chips
Meat Tenderizers	Pizza	Pretzels
Worcestershire Sauce	Luncheon Meats	Gatorade
Hot Dogs	Sausage, Chorizo	Pastrami
Salami	Ham	Bacon

COMMON MEASUREMENTS

1 ounces	=	30 cc	=	about one ice cube
4 ounces	=	½ cup	=	120 cc
8 ounces	=	1 cup	=	240 cc
16 ounces	=	2 cups	=	480 cc = 1 pound = ½ kilogram
24 ounces	=	3 cups	=	720 cc
32 ounces	=	4 cups	=	960 cc = 1 quart = 2 pounds = 1 kilogram

FOOD SAFETY

In General...

- Wash your hands with soap and warm water before and after handling food.
- Promptly wash cutting boards, plates and counter tops that come in contact with meat juices or raw meat. Use hot, soapy water. To sanitize after cleaning, put items through the automatic dishwasher or rinse them in a solution of 1 teaspoon of chlorine bleach and 1 quart of water.
- Contamination- Handle raw meat, poultry, seafood and eggs as if they were contaminated with bacteria. Even if they do not start out with enough bacteria to make you sick, if mishandled they could.

When Shopping and Preparing...

- Dented or damaged cans- Do not eat foods from dented or damaged cans.
- Freshness dates- Do not use food products after their freshness date has expired. Exception is milk which has a sold by date and is still good for another week.
- Raw eggs- Do not eat raw eggs or uncooked dough which contains raw eggs.
- Wash produce thoroughly with water. Use a scrub brush to remove dirt from potatoes, carrots, and turnips. Peel and discard outer leaves and rinds. Wash prepackaged salad mixes and vegetables, even if the label says they are pre-washed. No soap or detergent is needed.
- Purchase fresh produce-Do not buy any produce which is bruised, shriveled, moldy or slimy. Buy only what you can use within a few days.
- Thaw frozen foods in the refrigerator- not on the counter.
- Separate your cutting boards- Use one board for raw meat, poultry and fish and use another board for salads and other foods.

- Buy fresh fish. Seafood should have a clean smell. The fish eyes should be clear, shiny and bulging (not sunken).

When Cooking...

- Always cook thoroughly. Only thorough cooking will destroy any harmful bacteria in the food. Freezing or rinsing foods in water will not kill the bacteria.

PHOSPHORUS

Phosphorus is a mineral found in most foods. Normal kidneys help to get rid of phosphorus. When the kidneys no longer work or do not work well, phosphorus can build up in the blood. A high level of phosphorus in the blood can cause weak and brittle bones, bone pain and itching. Also, high phosphorus can cause calcium to settle inside your blood vessels. When the calcium builds up in the blood vessels they can become clogged. This can cause problems for your surgery.

Keeping your blood phosphorus in the normal range is very important in keeping you healthy. Your dialysis dietitian will tell you how much phosphorus you can eat in a day. If your doctor has ordered a pill for lowering phosphorus, you need to take it with your meals as ordered. These are some names of phosphorus binders:

- Phoslo
- Renagel
- Calcichew
- Basaljel
- *Tums
- * Calcium carbonate
- * Calcimix

HIGH PHOSPHORUS FOODS

DRIED BEANS

Black Beans
Blackeyed Peas
Chickpeas
Garbonzo Beans
Kidney Beans
Lentils
Lima Beans
Navy Beans
Pinto Beans
Red Beans
Refried Beans
Soybeans
White Beans

MAIN MEAL ITEMS

Cheese Enchiladas
Cheese Casseroles
Lasagna
Pot Pies
Salmon
Sardines
TV Dinners

STARCH ITEMS

Biscuits
Bran Cereals
Bran Muffins
Granola Bars
Oat Bran
Oatmeal
Wheat Germ

DAIRY ITEMS

Cheeses
Cottage Cheeses
Dried Milk
Fluid Milk (Whole, 2%,
Skim, Butter, Goat)
Milkshakes
Yogurts

MISCELLANEOUS

Cola Sodas
Chocolate
Nuts
Raisins
Seeds (Sunflower,
Pumpkin)

POTASSIUM

Potassium is a mineral found in most foods. Normal kidneys help to get rid of potassium. When the kidneys no longer work or do not work well, potassium can build up in the blood. A high level of potassium in the blood can cause the heart to stop beating and other muscles not to work right. Keeping the potassium level in your blood in the normal range is very important to your health.

Your dialysis dietitian will tell you how much potassium you can eat in a day.

HIGH POTASSIUM FOODS

FRUITS

BEANS

Apricots
Bananas
Peas
Cantaloupes
Dried Fruits (apricots,
Beans
Honey Dew Melons
Kiwifruits
Mangos
Oranges, Orange juice
Papayas
Tamarinds

DAIRY ITEMS

Dried Milk
Fluid Milk (whole, 2%

VEGETABLES

Acorn Squash
Artichokes
Avocados
Broccoli
Brussels Sprouts
Butternut Squash
Dark Leafy Greens
Guacamole
Hubbard Squash
Mushrooms
Nopales
Potatoes (baked, chips,
french fries, hashbrowns)
Spinach
Sweet Potatoes

DRIED

Black Beans
Blackeyed
Chickpeas
Garbonzo
Kidney Beans
Lentils
Lima Beans
Navy Beans
Pinto Beans
Red Beans
Refried Beans
Soybeans
White Beans

Social Services and Transplantation

Social Workers are a valuable asset to the transplant process. You will be able to discuss concerns and voice questions in many areas related directly or indirectly to your transplant.

Questions that come to mind may include:

- How will the transplant change my life?
- How will the transplant affect my family?
- What resources are available near the transplant hospital for out of town patients?
- How much will this cost me?
- How much will my medications be after transplant?
- Will my insurance cover my expenses?
- Will my insurance cover the expenses of a Living Donor?

These are a sample of the types of issues facing a patient choosing to have a transplant. Answers to these questions and many others can be obtained during your pre-transplant visit, as well as any other time when questions arise.

Your social worker will help you understand your feelings, prioritize your commitments and adjust your activities to meet the requirements of your new lifestyle. Problem solving is a method in dealing with most problems pre and post transplant. Your social worker is a good resource to help you in accomplishing necessary tasks related to preparing for your transplant, as well as post transplant.

Some of the services your social worker may provide:

- Referrals to pharmaceutical companies for help in
- obtaining medications.
- Community referrals for home care need if indicated.
- Emotional support and encouragement when needed.
- Community resources for vocational assistance.
- Referrals to financial aid programs as indicated.

Trough an interview, your social worker can find out what your needs are and provide referrals and resources that help you understand and cope with problems associated with your illness. As you learn more about your illness and the problems associated with receiving a kidney transplant, it is common to feel unsure of what you need to do and who to talk to. The social worker can be the individual that will help bridge you with those who can assist you in coping with your new kidney, as well as coping with the waiting period prior to a transplant.

Your family may also experience concerns and have questions, which can also be addressed by the social worker. Again, the social worker can provide necessary resources and support to family members and others in coping with your transplant process.

TRANSPLANTATION AND FUNDING

Many questions and concerns come to mind about affording a transplant. Few patients and families are able to pay all the costs of transplantation from a single source. Most often you will rely on a combination of funding sources.

What you need to know may include:

- ◆ Will my insurance cover the cost of hospitalization, outpatient follow up care and medications?
- ◆ Will there be expenses out of pocket, not covered by insurance?
- ◆ How do I qualify for assistance with the State?
- ◆ What happens if I can't afford my medications after a transplant?

Most insurance policies have some sort of lifetime maximum amount or “cap” on the benefits they will pay on your behalf. Once a patient has reached this amount, the insurance company does not have to pay any additional benefits. The amount of these “caps” varies depending on the individual policy. It is important to be familiar with the amount and terms of your insurance “cap”.

It is best to make any necessary arrangements with your insurance company prior to transplant. Many companies require prior authorization/approval for organ transplant procedures.

Questions you may want to ask your insurance company include:

- ◆ Is there an assigned individual who strictly works with transplant cases?
- ◆ What is the “cap” on my benefits?
- ◆ Is there deductibles I have to pay?
- ◆ Does my insurance cover medications indefinitely, since most of my medications will be needed for the rest of my life?

Though funding issues can be worrisome, it is important to discuss these issues at length with the Transplant Center’s Social Worker. Please keep this Social Worker advised of any changes in your coverage and funding.

MEDICARE COVERAGE

At present, MEDICARE offers coverage to its beneficiaries for kidney, heart, lung and liver transplants. This coverage currently includes payment for a number of the direct costs of the transplant operation. One cost in particular is the MEDICARE PART B benefit for immunosuppressant medications. At this time MEDICARE will cover 80% of the 3 immunosuppressant medications. If you receive Social Security Disability Income or are over the age of 65, your 80% Medicare coverage for these specific medications will be for the life of your transplanted organ. If you receive Medicare benefits primarily due to your End Stage Renal Disease, the 80% Medicare coverage for these medications will be expected to terminate at the end of 3 years after transplant. If you have another DISABLING CONDITION that is documented and validated by SOCIAL SECURITY AND MEDICARE it is likely your Medicare benefits will remain intact.

In order to maximize your MEDICARE benefits you must go to a MEDICARE APPROVED TRANSPLANT CENTER. Methodist Specialty and Transplant Hospital is an approved MEDICARE TRANSPLANT CENTER.

Questions you may have regarding MEDICARE may include:

- ◆ How do I apply for MEDICARE?
- ◆ Is there a waiting period before I receive benefits?
- ◆ What happens if I'm denied MEDICARE?
- ◆ Will having savings accounts effect my qualifying for MEDICARE?

In order to appropriately answer your questions or concerns regarding these benefits, please contact your local SOCIAL SECURITY ADMINISTRATION. It is through this office you will be assessed, reviewed and provided your MEDICARE benefits.

If you receive DISABILITY BENEFITS, i.e. a Social Security Disability Income check, you will automatically be enrolled in MEDICARE 2 YEARS LATER.

MEDICARE is divided into 2 parts:

PART A: Covers basic hospital care and some types of follow up treatment, i.e. home health care services.

PART B: Covers usual and customary visits with your physician, lab work and 80% of immunosuppressant medications.

MEDICARE DOES NOT COVER 100% of charges in most situations. MEDICARE usually pays hospitals and healthcare providers on a fixed fee schedule. You will have hospital deductibles and many other expenses not covered by MEDICARE. It is important to consider your options related to obtaining a MEDICARE SUPPLEMENT or MEDI-GAP policy.

Questions you may consider when looking into MEDICARE SUPPLEMENTS:

- ◆ Will this policy pay the hospital deductible?
- ◆ How expensive is this policy?
- ◆ Are there assistance programs to help purchase these plans?
- ◆ Can I be denied getting a MEDICARE SUPPLEMENT?

We recommend you talk with your local insurance agent about these policies.

TEXAS MEDICAID COVERAGE

The Texas Medicaid Program covers the cost of kidney transplants. Coverage is limited to a lifetime benefit of one initial transplant and one subsequent re-transplant.

Prior authorization is needed prior to this surgery. This will be obtained through the Transplant Center. You may need to follow up to verify authorization has been obtained prior to surgery.

It is necessary to note that Medicaid does not cover the medical expenses for a Living Donor transplant. Methodist Specialty and Transplant Hospital will however waive these costs for these individuals.

The Medicaid program has limited funds for medication assistance. You will need to know if your type of Medicaid benefit offers you this coverage on an unlimited or limited basis. There are some Medicaid benefits that do not include any medication coverage. Please be sure to check with your Department of Human Services Caseworker to be clear as to which type of benefits you are currently covered by and which you may be eligible for in the future, based on medical and financial changes you may incur.

Some types of Medicaid benefits you may wish to apply for include:

- ◆ **MQMB – MEDICAID QUALIFIED MEDICARE BENEFICIARY.**
This program is for those individuals already covered by MEDICARE. The benefits will include 3 prescriptions per month and the 20% co-insurance costs of your hospitalization, your hospital deductible, as well as the 20% costs of your Medicare Part B benefits, i.e. lab tests, doctor's visits and 3 immunosuppressant medications.

- ◆ QMB – QUALIFIED MEDICARE BENEFICIARY. This program is for those individuals already covered by MEDICARE. These benefits include the 20% co-insurance costs of your hospitalization, your hospital deductible and the 20% costs of your Medicare Part B benefits, which include lab tests, doctor's visits and 3 immunosuppressant medications.

Questions you may have about your Medicaid benefits may include:

- ◆ Are there outstanding costs I will have for the hospitalization?
- ◆ What happens if I lose my Medicaid benefits?
- ◆ How long will my Medicaid benefits cover my immunosuppressant medications?

Your MEDICAID benefits are reviewed regularly and any changes in your income will effect your continued access to MEDICAID. ANY CHANGES TO YOUR INSURANCE COVERAGE, INCLUDING DISCONTINUANCE OF MEDICAID NEEDS TO BE REPORTED TO THE TRANSPLANT CENTER. This is most significant for those who are on a cadaver waiting list. This will give the Social Workers and opportunity to assist you in finding the appropriate funding to help with the costs of hospitalization and medications post surgery.

TEXAS KIDNEY HEALTHCARE (KHC)

The Texas Kidney Healthcare program is a state renal program that was established to financially help the renal failure patient. It is DIFFERENT from Medicare and Medicaid. If you have been diagnosed with End Stage Renal Disease and have started treatment for renal failure you should apply for assistance through this program. The Texas Kidney Healthcare program recognizes treatment for renal disease patients as any form of dialysis or kidney transplants. Please discuss your eligibility for this program with your dialysis clinic Social Worker who can assist you in the application process. If you have not started dialysis and have a kidney transplant, the Transplant Social Worker will assist you with this application process.

There are 2 major criteria a renal disease patient must meet to qualify for this program.

- ◆ You must be a resident of Texas
- ◆ Annual adjusted gross income must be under \$60,000 per year.

You will be requested to provide residency documentation and income information at the time you make this application.

Your benefits under this program include transportation costs and medications costs such as:

- ◆ Mileage reimbursement for patient transportation.
- ◆ A monthly maximum transportation allowance.
- ◆ 4 roundtrips per month for transplant patients, to include the trip for the transplant surgery.
- ◆ 4 prescriptions per month if you DO NOT have insurance or a prescription card. These medications will need to be related to your kidney disease treatment.

Exclusions from these benefits are:

- ◆ If you have Medicare, your anti-rejection medications will not be covered, unless your Medicare is discontinued. You will need to have documentation from Social Security if your Medicare benefits stop.
- ◆ If you have Medicaid and have the prescription benefit covered under this State program, Texas Kidney Healthcare will only cover 1 medication per month.
- ◆ If you have Medicaid and you have the transportation benefit, The Medical Transportation Program (MTP) will be your primary source for transportation reimbursement. The Medical Transportation Office needs to be contacted BEFORE your medical appointments, to include when you come for transplant surgery.

Often Texas Kidney Healthcare is mistakenly called “The Kidney Foundation”. It is important to recognize the limits this program has and how it differs from other national organizations like the National Kidney Foundation or The American Kidney Fund. These programs have often assisted renal disease patients, primarily those on dialysis with financial assistance in obtaining Medicare supplements.

PLEASE BE AWARE OF HOW THESE PROGRAMS FUND YOUR NEEDS. ONCE YOU HAVE A KIDNEY TRANSPLANT, THESE PROGRAMS WILL STOP PAYING FOR YOUR NEEDS, ESPECIALLY PREMIUM PAYMENTS TOWARD YOUR MEDICARE SUPPLEMENT.

Your clinic Social Worker in the dialysis center can assist you with your options for assistance for programs that will make dialysis more affordable.

Military Benefits/Programs for Transplant

There are several options available to potential kidney transplant patients through their military benefits programs.

Champus: This program is the Civilian Health and Medical Program of the Uniformed Services, established in 1966. This government funding is for families of active duty, retired or deceased military personnel. We recommend you contact the Health Benefit Advisor at the nearest facility to you for more information.

V.A. Benefits: This program is through the Veteran's Administration. This is designed around the healthcare needs of those military personnel and their dependents that first became ill while in the military service and are indigent as defined by the Veteran's Administration. This program may assist with medications for transplant patients. We recommend you contact your local Veteran's Administration office for additional details about how to access this program.

Tricare: This program is designed for the healthcare needs of military personnel and their dependents. When a beneficiary develops kidney failure and is eligible for Medicare benefits, the beneficiary must apply for Medicare. Tricare will become secondary to Medicare the day Medicare becomes effective. You will lose Tricare benefits if you do not apply for Medicare. We recommend you contact the case manager for Tricare for additional details.

DISCHARGE FROM THE HOSPITAL

While you are in the hospital, the transplant team will prepare you for discharge by teaching you everything you need to know about caring for your new kidney. You will learn:

- All about your medicines
- How to prevent infections
- How to identify rejection
- What you can or cannot eat
- When you can return to daily activities
- When you can exercise
- When you can return to work

When you are discharged from the hospital, you may have to go to a hotel and stay a few days until everything is stable or completed before you go home. Then when you go home, you will continue being seen by the transplant surgeon and by your own doctor. Blood work will be done once or twice a week and eventually taper to once every 4-6 months. Appointments for blood work and doctor visits will be set up for you by the transplant coordinator. It is very important to keep all appointments because often rejection or other complications can be identified and treated before they become a problem.

Remember: Transplantation is another treatment for renal failure, there is no cure. You must take an active role in your life with a transplant.

Why Choose A Transplant?

Although transplantation is not for everyone, it does give a chance for a more normal life. The success of the transplant depends a great deal on you. If you keep your appointments with the doctor and take your medications as instructed, then you greatly increase your chance of being rewarded with a healthy, functioning transplanted kidney. Reasons to help you decide to choose or decline a transplant are listed below.

Benefits

- No dialysis
- No fluid or diet restrictions (unless you are Diabetic)
- More energy
- More freedom to travel
- You can return to work
- You are able to live a more “normal” life

Drawbacks

- Not a cure
- You have to take medicines for the rest of your life
- The medicines have side effects that affect everyone differently
- May get Diabetes from one of the medicines
- May get complications such as infection or rejection
- The kidney may not work at all or for only a short time

Discuss transplantation with your family and doctors to be sure you are making the decision that is right for you. If you have any questions about transplant or donation, you can call our coordinators at 1-800-888-0402.

What Next?

Now you have completed your general orientation and evaluation for transplant. You must:

- Decide whether or not you are interested in transplant and let us know.
- Finish your evaluation if you are interested.

The next part of the evaluation will include any or all of the following:

- A letter notifying your nephrologist and you of what tests are needed to complete the evaluation.
- Completion of whatever testing is necessary, either here or with your nephrologist. All copies of results must be sent here to be reviewed by the transplant team.
- Start donor evaluation once your testing has been completed.
- Insurance clearance will be done by us once you and your donor have completed all testing and cleared by the transplant team
- Schedule surgery
- Add to the waiting list

You will be working very closely with the transplant team to assure that your evaluation is completed in a timely manner. If you have any questions, please call one of the transplant coordinators.

Directions and Important Phone Numbers

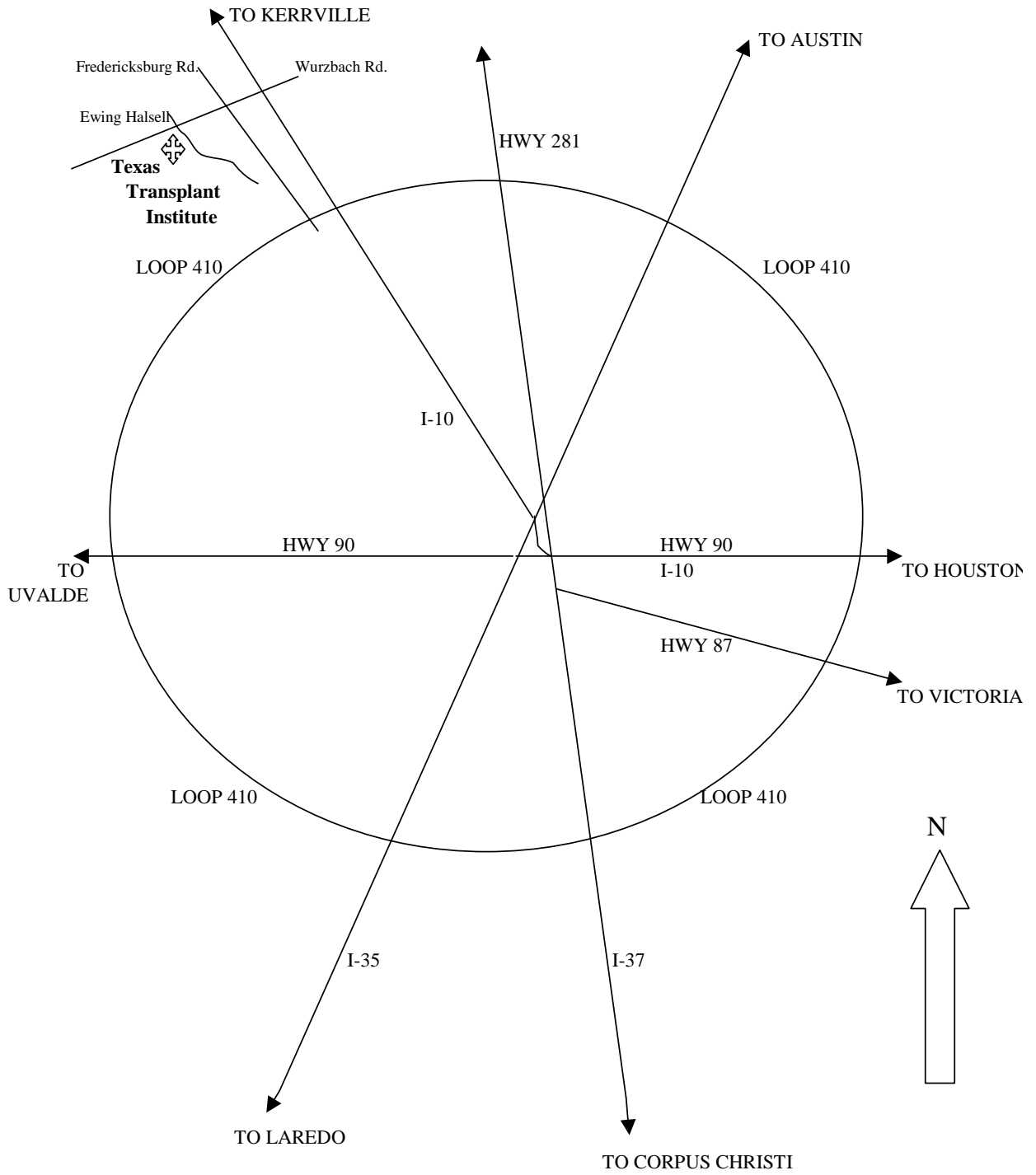
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Transplant Clinic – San Antonio Telephone : 210-575-8400
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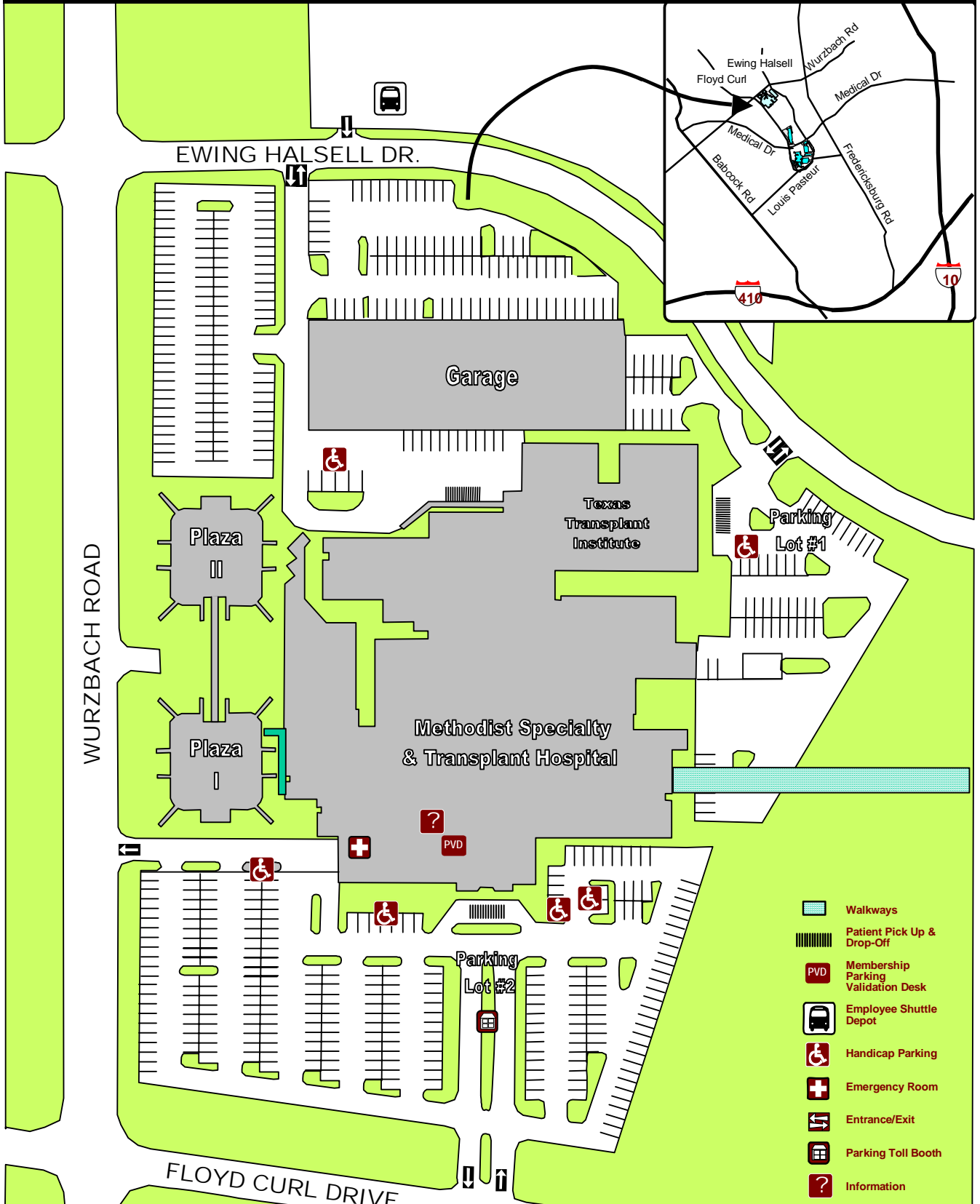
Transplant Clinic – McAllen Telephone : 956- 688-6264
Fax : 956-688-6265








Transplant Clinic – Corpus Christi Telephone : 361-884-2809
Fax: 361-884-2781

Toll Free Phone Number 800-888-0402



Texas Transplant Institute



-  Walkways
-  Patient Pick Up & Drop-Off
-  Membership Parking Validation Desk
-  Employee Shuttle Depot
-  Handicap Parking
-  Emergency Room
-  Entrance/Exit
-  Parking Toll Booth
-  Information

(210) 575-8425 or (800) 888-0402: 8201 Ewing Halsell

