

## **INFORMATION AND CONSENT FORM FOR PROCESS OF KIDNEY TRANSPLANT AT ST. MICHAEL'S HOSPITAL**

### **INTRODUCTION**

Welcome to the transplant program at St. Michael's Hospital. The transplant team is composed of doctors, nurses, social workers, pharmacists and a dietician who will help you throughout your kidney transplant experience. This form is not intended to replace a thorough discussion with the transplant team.

We realize this may be an anxious time for you and your family. You will receive thorough teaching and counseling throughout the different stages of the kidney transplant process. Please feel free to contact us if you have any questions in regard to transplantation at any time.

#### **Interpreter**

If you need an interpreter, please call the transplant office at (416) 867-3665 ahead of time so we can arrange for one prior to your visit.

### **OBJECTIVES**

The letter of information and consent that you are about to read and review with the transplant team has been created to achieve the following objectives:

- To inform you about the benefits and risks involved in getting a kidney transplant
- To inform you about the different steps that must be completed before getting a kidney transplant
- To inform you about your options if you decide that a kidney transplant is not the best choice for you
- To inform you of the different options for kidney transplantation within our program

- To help you plan for financial and lifestyle changes that may occur after your transplant
- To share with you the roles and responsibilities of each member of the transplant team
- To inform you about your responsibilities in caring for your kidney transplant
- To obtain consent for placement on the transplant list

## **WHAT ARE THE BENEFITS OF A KIDNEY TRANSPLANT**

There are many reasons why some people decide to have a kidney transplant. Some of those reasons include freedom from dialysis that allows for fewer food restrictions, greater freedom to travel and possibly return to work and have a more active lifestyle. After transplant, many patients may experience improvement in quality and length of life. **It is important to realize that a kidney transplant is not a cure for kidney disease but that it is another form of treatment.**

## **WHAT ARE THE RISKS INVOLVED IN GETTING A TRANSPLANT?**

A kidney transplant is not the best option for everyone. It is very important that you are aware of and understand what risks are involved in having a kidney transplant. Please make sure to talk to the transplant team if you have any questions or concerns.

## **TRANSPLANT SURGERY**

Includes surgical complications (eg. wound problems, bleeding, infection, fluid collections, or death).

## **MEDICATION SIDE EFFECTS**

### **Transplant Medications**

Your immune system is your body's natural defense system working to protect your body from infection. You will need to take medications to keep your immune system functioning at a lower level to help prevent the transplanted

kidney from being damaged by the immune system. In other words, they help to prevent rejection of your transplanted kidney.

All medications that lower your immune system including your transplant medications, increase your risk of developing certain infections and cancers, both of which can be life threatening.

You will be taking a combination of a few of the following medications. Listed below, you will find some potential side effects that may occur. Adjustments in medications may be made by the transplant team if particular side effects are bothersome.

**Tacrolimus (Prograf):** Include diabetes (approx. 10 % risk), headache, hand and feet tingling, tremors, hair loss, problems with transplanted kidney function.

**Cyclosporine (Neoral):** Include headaches, tremors, swollen gums, acne, increased hair growth, hand and feet tingling, problems with transplanted kidney function, high blood pressure, diabetes (approx. 4% risk), increased cholesterol levels and gout.

**Prednisone:** Include weight gain, indigestion, nervousness, acne, skin rash, swelling of face, feet and ankles, diabetes (approx. 10% risk), mood changes, slower wound healing, bone thinning, bruising, increased cholesterol levels.

**Mycophenolate Mofetil (Cellcept):** Include nausea, vomiting, diarrhea, low white blood cell count.

**Sirolimus (Rapamune):** Increased cholesterol levels, anemia, edema (swelling)

### **Other Types of Medications You May Be Required To Take After Your Transplant:**

Include blood pressure pills, cholesterol- lowering pills, antibiotics to prevent or fight infection, iron to help increase your hemoglobin, stool softeners to help prevent constipation, additional medications to fight a rejection episode.

## **WHAT ARE THE ALTERNATIVES TO KIDNEY TRANSPLANT?**

If you decide that a kidney transplant is not the best option for you right now, you will continue with your current dialysis routine. If you change your mind in

the future, you may contact the transplant team to be reconsidered for a kidney transplant.

## **HOW WELL AND FOR HOW LONG CAN YOU EXPECT THE KIDNEY TRANSPLANT TO WORK?**

### **Living Donor Transplants:**

<b>Time length</b>	<b>Working kidney</b>
By end of first year	90 – 95 %
By 5 years	80 %
By 10 years	65 %

### **Deceased Transplants:**

<b>Time length</b>	<b>Working kidney</b>
By end of first year	85 – 90%
By 5 years	75%
By 10 years	50%

## **WHAT IF YOUR KIDNEY TRANSPLANT STOPS WORKING?**

When a transplant stops working well in the first year after the surgery, it is usually because of technical problems, a severe acute rejection episode or chronic rejection. A rejection episode happens when your immune system recognizes that the transplanted kidney is not your own and tries to get rid of it. Your transplant medications work to help keep your immune system work at a lower level.

However, sometimes even when you do everything right, your body may try to reject your transplanted kidney. When this happens, you may have a biopsy performed on your transplanted kidney and you will be given rejection fighting medication. If these medications are not successful, you will either immediately or eventually have to return to dialysis.

## **WHAT FINANCIAL AND LIFESTYLE ARRANGEMENTS MAY CHANGE AFTER YOU HAVE HAD A KIDNEY TRANSPLANT**

### **Disability Benefits:**

After transplant, your disability benefit provider (LTD, CPP-D, ODSP) may not consider you disabled with respect to problems related to kidney failure. As a result you may lose your benefits. It is important that you seek employment options before your benefits stop.

### **Transportation:**

After transplant you may not be eligible for Wheel Trans. You will need to think about transportation to and from clinic.

### **Prescription Costs:**

Before you receive your kidney transplant, you **MUST** arrange to cover the cost of all your medications. **You will not be transplanted until these arrangements have been made.** If you need assistance with the above, please contact your social worker.

## **WHAT ARE YOUR RESPONSIBILITIES TO YOUR TRANSPLANTED KIDNEY?**

You play a very important role in helping your kidney transplant to be a success.

### **Bloodwork:**

Please follow the schedule of bloodwork and clinic routine.

### **Medication Compliance:**

It is very important that you take your medications EXACTLY as you are instructed. If you have concerns about the medications you are taking or are experiencing side effects, call the transplant office and speak to a nurse. **DO NOT MAKE CHANGES TO YOUR MEDICATIONS WITHOUT TALKING TO THE TRANSPLANT NURSES OR DOCTORS FIRST.** Keep the transplant team aware of all medications (i.e. herbal, blood pressure, drugs from other physicians, etc.)

## **Clinic Visits**

You are expected to attend regular visits at the transplant clinic at St. Michael's Hospital. You must call to cancel and reschedule your appointment if you are unable to attend. The clinic appointments are important as you will have the opportunity to review your medications and diet, discuss any health concerns that may have developed and for the doctors and nurses to review your bloodwork and make sure you are healthy.

## **WHAT OTHER INFORMATION DO YOU NEED TO KNOW?**

### **Returning to Work**

It is expected that once you have had your kidney transplant, you will be able to return to the activities you did before starting dialysis, including work. Once everything is going well, it is expected that you will no longer be on disability for reasons related to kidney failure within a reasonable length of time.

### **Research Studies**

You may be asked to consider research studies both before and after you have your kidney transplant. You are free to choose whether you would like to get involved in research studies. If you choose not to participate in a research study, your care at St. Michael's Hospital will not be compromised in any way nor will the attitude of the staff towards you change in any way.

## **WHAT IS INVOLVED IN GETTING A KIDNEY TRANSPLANT?**

### **Step 1: Getting Onto the Transplant List**

- First, you need to be on dialysis unless you have a living donor available.
- You will be referred to the Transplant Program.
- You will need to have many tests completed to help us assess your suitability to have a transplant.
- You will have an appointment to meet with the transplant team. Once all of your medical and social information has been collected and you have been approved by the transplant team, you will be tissue typed. Tissue typing is a special blood test that will tell us your genetic makeup and help us to match you with a potential kidney donor.

## **Step 2: Evaluating Potential Living Donors**

- If someone is interested in obtaining information about being a living donor, have them contact the living donor team. The living donor team will evaluate whether it is possible for your potential kidney donor to donate a kidney to you. Living donor kidney transplants offer the additional benefit of shorter waiting times and somewhat better long-term outcomes compared to deceased kidney transplants.

## **Step 3: Waiting, Waiting, Waiting**

- *Waiting Times:* you can expect to wait at least 5 – 9 years once you have been placed on the kidney transplant list.
- *On Hold:* if you are having significant new health or social problems (eg. have been admitted to hospital/surgery, etc.) or old health problems that are getting worse, you have to be placed “on hold”. While you are on hold, you will remain on the transplant list but you will not be called for a kidney transplant until the problem is resolved and your health centre has informed the transplant team at St. Michael’s Hospital.
- *Contact information:* make sure we have your correct telephone numbers.

## **Step 4: When You Get The Phone Call.....**

- You will be asked about your current health, recent blood transfusions and may be asked to come to St. Michael's Hospital to be seen by a doctor who will make sure that you are healthy enough for surgery.
- **Do not eat or drink anything.**

- Sometimes, a second person is called to come in for the same kidney. This is done so that less time is wasted, if it turns out that the first person is not healthy enough nor compatible to have the transplant. It is important to keep in mind that you may be sent home even after you have been called for a transplant. Remember that if you have been called once, your turn may come again relatively soon.

### **Step 5: After You Have The Kidney Transplant Surgery**

- You will probably be in the hospital for 7 – 10 days. During this time you will be visited by many different people from the health care team. The transplant pharmacist will review your new medications with you and answer any of your questions or concerns. The transplant dietician will teach you in clinic about changes that you can make to your diet since you will no longer be on dialysis. The transplant nurses will review information with you before you go home from the hospital.

### **Step 6: After You Go Home**

- You will be followed up in the outpatient Renal Transplant clinic. Initially the visits will be a **minimum** of two times a week for at least the first month.

## **TRANSPLANT TEAM PHONE DIRECTORY**

### **Transplant Nurse Coordinators**

(416) 867-3665

Thelma Carino

Jennie Huckle

Meriam Jayoma

Galo Meliton

Fernanda Shamy

### **Social Worker**

(416) 867-3706

**Transplant Nephrologists**

Dr. Jeffrey Zaltzman (416) 867-7444  
Dr. Ramesh Prasad (416) 867-3722

**Transplant Surgeons**

Dr. Honey (416) 867-3705  
Dr. Stewart (416) 867-3686  
Dr. Pace (416) 867-3695

**Dietician**

Karen Burleigh (416) 867-2790

**Research Coordinators**

Michelle Nash (416) 867-3692  
Lindita Rapi (416) 867- 7460 ext 8024

**TRANSPLANT CONSENT AGREEMENT**

By signing below, I will be placed on the kidney transplant list once all requirements have been met. I understand all of the information listed above and have had the opportunity to have all of my questions and concerns answered to my satisfaction. I agree to all of the responsibilities listed above and will take care of myself and my transplanted kidney to the best of my ability. I will receive a copy of this consent form for my records.

\_\_\_\_\_  
transplant candidate (printed name)      \_\_\_\_\_  
transplant candidate (signature)      \_\_\_\_\_  
date

If it was necessary to have this form translated, the person translating the information will be required to read and sign the statement below.

### TRANSLATION AGREEMENT

I certify that I have translated all of the information in this letter of information and consent completely and accurately to the best of my ability.

I certify that I have asked all of the questions that the transplant candidate has asked through me and that I have accurately translated all of the answers.

I agree to be the translator for the transplant candidate's care after they have had their kidney transplant.

\_\_\_\_\_

name (print)

\_\_\_\_\_

address

\_\_\_\_\_

daytime telephone number

\_\_\_\_\_

evening telephone number

\_\_\_\_\_

language translated

\_\_\_\_\_

translator (signature)

\_\_\_\_\_

date