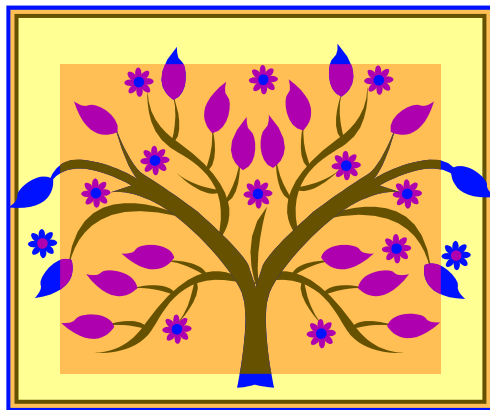


# *LIVING WITH KIDNEY TRANSPLANTATION*



*Providence*  
HEALTH CARE

How you want to be treated.

[www.transplant.bc.ca](http://www.transplant.bc.ca)

## **INTRODUCTION**

This booklet has been written to provide you with information about living with a kidney transplant. Please take some time to go through this booklet to help you to have a better understanding about kidney transplantation. Should you have any further questions, please contact us at the following numbers:

### **Vancouver Coastal Health**

#### **Program Coordinator \***

Kidney Pre-Transplant Service  
5<sup>th</sup> Floor, Solid Organ Transplant Clinic  
Gordon & Leslie Diamond Health Care Centre  
2775 Laurel Street, Vancouver, BC V5Z 1M9  
Phone: 604 875-5182  
Fax: 604 875-5236

### **St. Paul's Hospital**

#### **Clinical Nurse Leader and Patient Educator \***

Pre Kidney Transplant Program  
Ward 6A 1081 Burrard Street  
Vancouver, British Columbia  
V6Z 1Y6

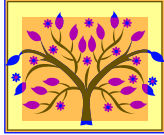
Phone: 604 806-9078  
Fax: 604 806-9658

### **British Columbia's Children's Hospital**

Transplant Nurse Clinician \*  
4480 Oak Street  
Vancouver, British Columbia  
V6H 3V4

Phone: 604 875-3604  
Fax: 604 875-2943

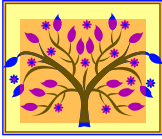
\* Referred to as transplant nurses in this booklet



## Table of Contents

<b>Chapter 1</b>	<b>Introduction</b>	<b>5</b>
I.	Overview of Transplantation	6
II.	Your Transplant Team	7
III.	The History of Organ Transplantation	8
IV.	How Your Kidneys Work	9
V.	How Kidney Failure Affects Your Health	11
<b>Chapter 2</b>	<b>Pre-Transplant Assessment</b>	<b>13</b>
I.	Being referred for transplant assessment	13
II.	Before you appointment	14
III.	Appointments with the transplant team	14
IV.	Completing the assessment	15
<b>Chapter 3</b>	<b>Living Donor Kidney Transplantation</b>	<b>17</b>
I.	Who can be a living kidney donor?	18
II.	Paired kidney exchange program	19
III.	Preparing for a living donor kidney transplant	20
IV.	Admission to the hospital	21
<b>Chapter 4</b>	<b>Deceased Donor Kidney Transplantation</b>	<b>23</b>
I.	The waiting list	24
II.	How the organs are allocated	24
III.	Stress during the waiting period	25
IV.	Monitoring your health	28
V.	Preparing for the call	29
VI.	Receiving the call for a deceased donor transplant	30

VII.	<i>The Gift of Life</i>	31
<b>Chapter 5</b>	<b>Your Transplant</b>	34
I.	The Transplant Surgery	34
II.	After the Operation	36
<b>Chapter 6</b>	<b>The Road to Recovery</b>	39
I.	Recovery on the transplant ward	39
II.	Anti-rejection drugs	43
III.	Other medications	48
IV.	Rejection episodes	49
V.	Chronic rejection	51
VI.	Infection	52
VII.	Cancer	54
VIII.	Becoming self-reliant	54
<b>Chapter 7</b>	<b>Adjusting to Your New Life</b>	55
I.	Monitoring your health	56
II.	Transplant clinic visits	57
III.	Medications and other costs	57
IV.	Routine health care	58
V.	Guidelines for healthy living	60
VI.	Driving	62
VII.	Travelling	62
VIII.	Sexual activity	63
IV.	Community resources	64
V.	When to call the transplant team	64



## **Chapter 1    Transplantation**

Learning that you have a serious illness is never easy. At times, you may feel that you are coping well. At other times, you may feel overwhelmed by emotion. Whether you were told of your illness only recently or some time ago, you may still find it hard to accept that this has happened to you.

Like others in your situation, you may have gone through a period of bargaining, making promises in return for good health. You may feel angry or depressed. You may resent the fact that your illness has forced you and your family to make lifestyle changes. Accepting these changes can be difficult, but with the support of your family, your friends, and your health care providers, you can learn to deal with your illness and its effects.

Transplantation offers you a second chance at life and hope for the future. You will also face new challenges and responsibilities. Life will be different after your transplant. You will have to make a lifetime commitment to taking care of your new kidney.

**This chapter describes:**

- I.            Overview of Transplantation**
- II.           Your transplant team**
- III.          The history of organ transplantation**
- IV.          How your kidneys work**
- V.            How kidney failure affects your health**

## I. Overview of the Transplant Process

The following summarizes the transplant process and the chapters of this booklet.

For more information see...

<b>Pre-transplant Assessment</b> Although transplantation is considered an established treatment for end-stage organ failure, it is not suitable for everyone, so every potential transplant patient must be carefully assessed before being approved for transplantation.	<b>Chapter 2</b>
<b>Living Donor Kidney Transplantation</b> <i>***A living donor transplant is the only way to receive a timely transplant***</i> If you have a possible living donor, they should contact the Living Donor Team at the transplant center that you have been referred to. The assessment of a potential living donor can take several months to complete.	<b>Chapter 3</b>
<b>Deceased Donor Kidney Transplantation</b> If you do not have a potential donor, and you are found suitable for transplantation, you will be placed on the Provincial Transplant Waiting List. The waiting period for a deceased donor kidney transplant has increased over the past few years and may take up to 5-10 years.	<b>Chapter 4</b>
<b>Your Transplant</b> Your kidney transplant will occur at either St. Paul's Hospital or Vancouver General Hospital, depending on the transplant center where you were assessed. You can expect to be in the hospital for about 5-7 days.	<b>Chapter 5</b>
<b>The Road to Recovery</b> After your transplant, there will be many new things to learn about. You need to learn about the medications you will be taking after a transplant including side effects and risks. You will also need to learn about rejection - what it is, what are the signs and symptoms, and how it is treated.	<b>Chapter 6</b>
<b>Adjusting to your New Life</b> After your transplant, there are many adjustments you will make in your life. You may feel stressed or overwhelmed. Learning how to take care of yourself can help you to deal with these feelings.	<b>Chapter 7</b>

## II. Your Transplant Team

Your transplant team consists of experts who will take care of you throughout the transplantation process. Some of the team members are described below, but you may also meet others. Every one is an important member of the team; however, the amount of time you spend with each will depend on your individual needs.

**Medical Transplant Specialist (Nephrologist):** - These nephrologists are specialized in kidney transplantation and the care of kidney patients. They are involved in your assessment, your health care before transplantation, and your long-term health care following transplantation.

**Transplant Surgeon (Urologist):** - These doctors are specialists in transplant surgery. They are involved in your assessment, perform the transplant surgery, and are responsible for your health care immediately after surgery.

**Social Worker:** - The social worker takes part in your evaluation and is available throughout the transplantation process to provide you and your family with emotional support, information, and counseling. They will also help you to make arrangements for the practical impact of the transplantation.

**Pre-Transplant Nurses:** - This nurse coordinates your pre-transplant assessment, and provides information on transplantation and your progress with the transplant assessment, to you, your family, referring specialist, and family physician. The pre-transplant nurse also provides you with direct access to other members of the transplant team.

**Transplant Nurses:** - These specially trained nurses care for you before and after surgery when on the transplant unit. They help to begin your rehabilitation and prepare you for going home by teaching you about your medications and how to look after yourself.

**Post-Transplant Clinic Nurses:** - These outpatient clinic nurses monitor your progress closely after the transplant and will be your contact and resource person when you go home.

**Clinical Pharmacist (primarily Post-Transplant):** - The pharmacist counsels you on your medications, and can answer any questions about them, their side effects and when you should take them. Before you leave the hospital you will meet with the pharmacist to discuss your medications regime.

**Dietitian (primarily Post-Transplant):** - The dietitian assesses your nutritional needs and helps you put together a personal dietary plan to keep you in the best possible health before and after your transplant.

**Chaplain (if requested):** - The staff from the pastoral care department is available to provide support to you and your family. They can help you with religious or spiritual needs.

## **British Columbia Transplant**

The British Columbia Transplant (BCT) was established in 1985 to administer/support solid organ transplant programs in BC. BCT supports organ retrieval. Vancouver is a major transplantation centre and participates in multi-centre trials and research projects.

**The BCT Philosophy:** The BC Transplant believes the health-restoring benefits of organ transplantation should be available to those individuals who meet medical and eligibility criteria in British Columbia.

**BCT Mission Statement and Role:** The BC Transplant leads and coordinates all activities relating to organ donation and transplantation throughout BC, ensuring high standards of quality and efficient management.

**BCT** is affiliated with the province's three transplant hospitals. Vancouver General Hospital transplants kidneys, kidney/pancreas, lungs and heart/lungs, livers, and islets. St. Paul's Hospital transplants hearts and kidneys, and Children's Hospital transplant kidneys.

There are seven regional transplant clinics located throughout the province, which are closely linked to the transplant hospitals and BCT. These clinics may provide follow-up care after your transplant.



### **III. History of Transplantation**

Transplantation has become a well-recognized treatment option for people with organ failure. Three major factors have made transplantation a success: 1) advances in surgical techniques; 2) the discovery of anti-rejection medications; 3) an increasing public awareness of the need for organ donors.

Kidney transplantation is the preferred treatment option for most people with end-stage kidney disease. The first kidney transplants were performed between identical twins in the early 1950's without the use of anti-rejection (immunosuppression) medication. It wasn't until 1966 that deceased donor kidney transplants became a recognized form of treatment. The clinical use of cyclosporine (an immunosuppressive medication) in 1978 revolutionized transplantation with improved graft (kidney transplant) survival rates. The discovery and use of cyclosporine marked a new era in transplantation.

Today's scientific advances have changed kidney transplantation from an experimental procedure to a recognized form of treatment. Recent statistics show that a one-year graft survival rate can be better than 90%. The percent of acute rejection episodes has significantly decreased with the discovery of many new and improved immunosuppressive agents (these will be discussed in depth in Chapter 6 of this manual), thus benefiting transplant recipients and graft survival enormously.

Living kidney donation has become widely accepted, becoming a valuable alternative to deceased donor transplantation. The success rate for recipients of living donor kidneys is higher than for recipients of deceased donor kidneys. Shorter cold storage times and shorter waiting time for transplant have a great impact on the success of the kidney transplant and patient survival. The BCT booklet, "Donating a Kidney", can be provided for more information.

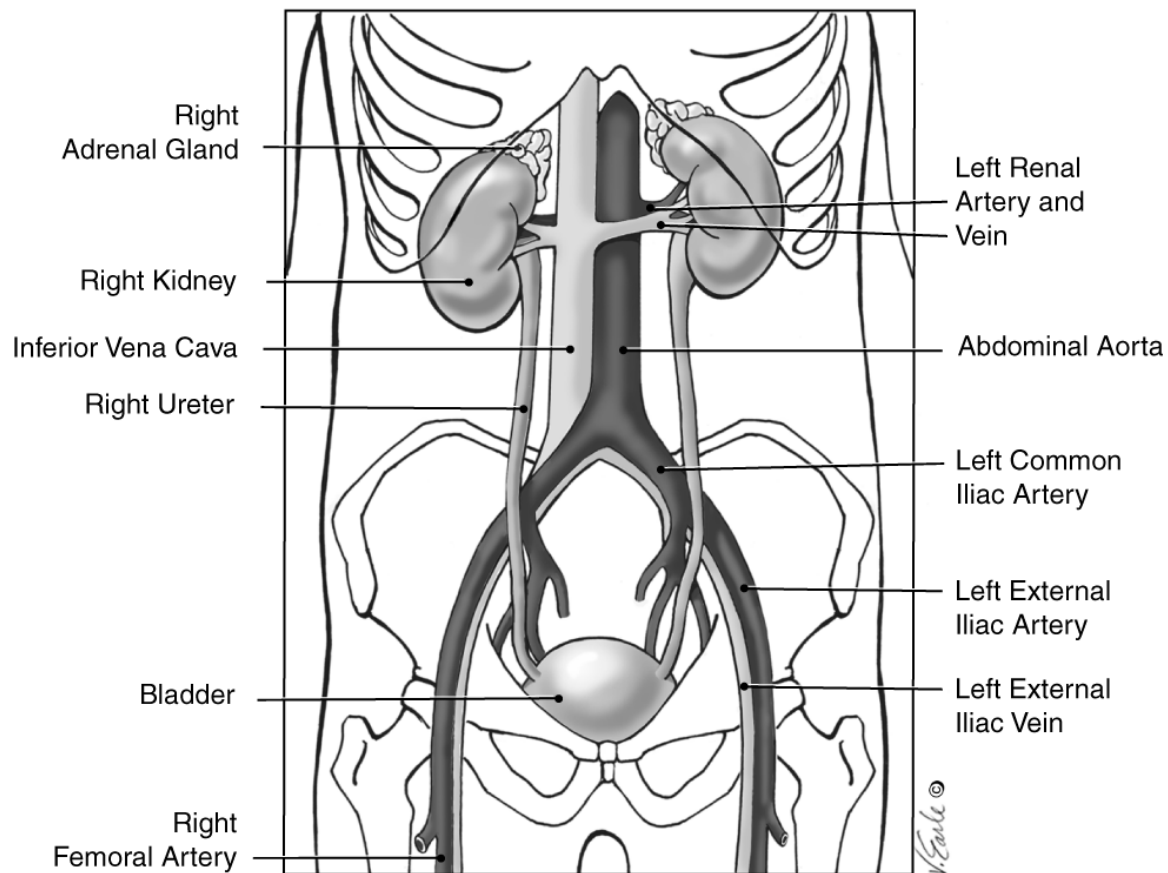
## **IV. How Your Kidney Works**

Kidneys function to keep the body in balance (called homeostasis), by controlling the composition and volume of blood.

### **The kidneys have three important functions:**

1. Kidneys maintain fluid balance-regulating water, removing excess or retaining water as needed.
2. Kidneys remove wastes and balance the blood's chemistry. Our kidneys work to regulate sodium, potassium, and phosphate levels to ensure adequate health. Wastes such as urea and creatinine must be removed from the body. Urea is formed through the breakdown of proteins. Creatinine is a product of muscle breakdown. Urea and creatinine levels are carefully monitored as they provide your doctor with useful information about the amount of kidney function you have.
3. The kidneys also have several hormonal roles, including production of erythropoietin (a substance necessary for the production of hemoglobin), renin (a substance involved in blood pressure control), and activation of vitamin D.

The urinary system consists of two kidneys, two ureters, one bladder, and one urethra. The kidneys, reddish-brown in colour, are situated one on either side of the spine, under the ribs. They are shaped like a kidney bean, each the size of a clenched fist. It is not uncommon to have minor variations in this anatomic arrangement, for example, two arteries, two ureters, etc.

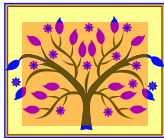


## V. How Kidney Failure Affects Your Health

Kidney failure occurs when the normal functions of the kidney are affected to varying degrees. When kidney failure is mild or moderate, treatment may include drug therapy and dietary changes, but when it is severe, artificial kidney treatment is necessary in order to maintain life. Dialysis is a reasonable treatment option but for some people transplantation may be better.

For more information regarding kidney function and treatment options please refer to the *Kidney Foundation Manual - Living with Kidney Disease*.





## **Chapter 2      Pre-Transplant Assessment**

Although transplantation is considered an established treatment for end-stage organ failure, it is not suitable for everyone, so every potential transplant patient must be carefully assessed before being approved for transplantation.

**This chapter describes:**

- I.      Being referred for transplant assessment**
- II.     Before your appointment**
- III.    Appointments with the transplant team**
- IV.    Completing the assessment**

### **I.      Being referred for transplant assessment**

If you are wondering about transplantation, or would like to be considered for a transplant, speak to your own nephrologist. Your nephrologist will review your case and the criteria for transplantation. If s/he thinks you are a suitable candidate for assessment, they will refer you to one of the transplant centers in Vancouver. Your information will be registered with the BC Transplant Society as “waiting to be reviewed”.

If you are wondering if you have been referred for transplant assessment, you can call one of the transplant centers to confirm what your status is.

## **II. Before your transplant appointments**

Your transplant center will send you information once this referral is received. You may receive requisitions to have additional blood work or testing done. Special blood tests to determine not only your kidney function, but also to evaluate liver function, exposure to a number of common viruses, cholesterol profile, and blood type will be requested. A chest x-ray and electrocardiogram may also be requested.

***\*\* It is very important you get this testing done, and then call the transplant center to let them know. There are many people waiting for appointments with the Transplant Teams, and you may not be booked until these results are available. \*\****

While you are waiting for your appointments with the Transplant Team, you can make sure your basic health and dental care is up to date:

- ❖ Go and see your dentist to make sure you have no infections in your mouth or teeth
- ❖ Women should make sure their Pap test and mammograms are up to date\*. Talk to your family doctor.
- ❖ Men should make sure their prostate testing is up to date. Talk to your family doctor\*.

\* Please have your family doctor forward this information to your transplant center\*

## **III. Coming for appointments with the transplant team**

Once the medical testing is reviewed, you will be given appointments in Vancouver for a complete assessment by the Transplant Team. As part of the initial assessment, you will be interviewed by various team members to determine whether transplantation is the best treatment option for you. You will also receive information that will help you make a decision regarding transplant. The goal of the assessment phase is to find out whether transplant is a safe and reasonable procedure for you, and whether transplantation is right for you.

**Your initial assessment will include:**

- ❖ Assessment with the transplant surgeon (urologist)
- ❖ Assessment with the transplant physician (nephrologist)
- ❖ Assessment with the transplant nurse and/or social worker.

You are encouraged to bring a support person with you. If you live outside of the lower mainland and require assistance in getting to these appointments or have financial concerns, please speak to your social worker.

#### **IV. Completing the assessment process**

Once you have met the Transplant Team, the physician and surgeon will write a letter to your own nephrologists and family doctor. Your file will be discussed at Transplant Rounds, where the doctors, nurses, and social workers meet together. This is where a decision is made about your suitability for transplantation.

After meeting with the Transplant Team, it is not unusual for additional tests to be ordered to determine your physical ability to undergo surgery and achieve a good quality of life. In some instances, arrangements will be made for patients to be seen by additional specialists. The goal is to enable you to be fit for transplant.

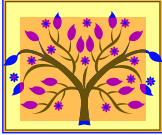
***\*\*It is important that you call your transplant center to let them know when you have completed any additional tests. This will help prevent delays in your assessment\*\****

Depending on what testing needs to be completed, it may take several months to arrange. Once all necessary test results are available, a decision will be made about your suitability for transplantation. If you have a potential living donor who has also been approved, a transplant date can be selected (see Chapter 3).

If you do not have a living donor, you will be placed on the Provincial Transplant Waiting List in the order of your dialysis start date. Because of the shortage of deceased donor organs, the waiting period for a deceased donor kidney transplant has increased over the past few years and may take up to 5-10 years (see Chapter 4).







## Chapter 3 Living Donor Kidney Transplantation

A transplant from a friend or relative is called *living donation*. With the increasing demand for kidney transplants, and the decreasing number of deceased donors, living donation is the only option for receiving a kidney transplant in a timely way.

Living donor kidney transplantation is a widely accepted and preferred treatment option for many people suffering from kidney disease. There are several advantages to a living donor kidney transplant over a deceased donor kidney transplant:

- ❖ Improved success rates
- ❖ Avoidance of lengthy waiting time
- ❖ Potential for transplantation before starting dialysis (pre-emptive transplantation)
- ❖ Ability to plan your surgery date

Detailed information regarding living kidney donation can be found in the booklet: *Donating a Kidney: British Columbia's Living donor Kidney Program*.

This chapter describes:

- I. Who can be a living kidney donor?
- II. Paired kidney exchange program
- III. Assessment of a potential donor
- IV. Preparing for a living donor kidney transplant
- V. Admission to the hospital for a living donor kidney transplant

## **I. Who can be a living kidney donor?**

Living kidney donors are people who choose to donate one healthy kidney. In most cases, the donor and recipient are family members, friends, or otherwise emotionally related to each other.

If someone would like to be assessed as a potential living donor, they should contact the Transplant Team at the center that you have been referred to (please see the contact numbers at the front of the booklet).

## **II. Assessment of a potential donor**

The work up of a donor is extensive as they must be absolutely healthy and we need to ensure the risks to them are minimal. We also want to maximize the chances of a successful transplant. The assessment of a potential donor can therefore take several months. The assessment of a potential donor is confidential and separate from the assessment of the recipient. Therefore, we cannot share information about a donor's assessment without their permission.

It is critical to determine whether the potential donor and the recipient are compatible. The important compatibilities are determined by blood tests. The tests are:

- ❖ Blood typing
- ❖ Crossmatching

### **Blood Typing**

This is the first test done, as usually the donor and the recipient must be blood type compatible. There are four major blood group types: A, B, O, and AB. Blood type can be determined using a small sample of blood. Please see the chart on the following page to see who you could receive a kidney from.

## Blood Typing: Who can I receive a kidney from?

I am blood type...	I can receive a kidney from...
A	A or O
B	B or O
AB	A, B, AB, or O
O	O

**Please note: It is not necessary for the donor and recipient to have the same Rh (rhesus) factor + or -**

### Crossmatching

If the donor and the recipient are blood type compatible, a **crossmatch** will be performed. This blood test identifies the presence of antibodies in the blood of the recipient, which would attack the donated kidney as soon as it is transplanted. Therefore, if the crossmatch is **positive**, we cannot do the transplant. A **negative** crossmatch means there is no antibody reaction, and the donor assessment can proceed.

If your potential donor is not the right blood type, or you have a positive crossmatch with your donor, a new option may be available. Please see the next section on the **Paired Donor Exchange Program**.

## II. Paired Donor Exchange Program

Unfortunately, even if a potential living kidney donor is identified, they may not be able to donate because they are the wrong blood group or you have a positive cross match to their blood. Approximately 1/3 of donors are ruled out for this reason. If no other donor is identified, the potential recipient may face a long wait for a deceased donor kidney transplant.

The British Columbia Transplant has initiated a new program aimed at helping recipient and their families when traditional avenues for living donation have been exhausted. This program is called the ***Paired Donor Exchange Program***

In a paired exchange program, living kidney donors who are blood type incompatible or have a positive crossmatch with their intended recipient donate a kidney to a selected recipient who faces a similar situation with their own donor. In this manner, the two kidneys are 'swapped' between the two donor/recipient pairs.

**Interested patients and donors should contact their transplant center to learn more about this program.**

### **III. Preparing for a living donor kidney transplant**

Living donor transplants are scheduled following approval of both the recipient and the donor by the Transplant Team. The ability to arrange your schedule around the surgical date and your recovery time is one of the many benefits of Living Donor Transplants.

Although every consideration is given to the donor and the recipient's schedules, the availability of the transplant surgeon and the OR time is of primary importance. Occasionally due to medical emergencies or other hospital considerations a pre-scheduled surgery date must be re-scheduled.

Prior to your surgery you will receive detailed information regarding testing and the final preparations for your transplant surgery. Two weeks prior to the scheduled transplant surgery date, both you and your donor will have blood drawn for repeat crossmatch and virology testing. You will also be required to be in Vancouver 1-3 days prior to your surgery.

If you are from out-of-town it will be necessary for you to arrange accommodation for your days in Vancouver prior to your surgery. The transplant social worker will be able to help you with these arrangements. Your dialysis schedule will be arranged to optimize your condition before the Transplant. Out-of-town recipients usually have a dialysis run scheduled in Vancouver for the day before the surgery.

You may find it helpful to review the travel and preparation suggestions found on page 30 of this booklet.

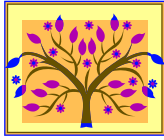
#### **IV. Admission to hospital for a living donor kidney transplant**

You may attend the pre-admission clinic for final testing and then be admitted the day of your surgery, or you may be admitted to the hospital the day before your transplant. Final testing includes blood work, a chest x-ray, and ECG (electrocardiogram). You will be assessed by a transplant physician who will write your transplant orders. You will also meet with an anaesthetist and a nurse. Pre-operative teaching will be done and any other medical testing will be arranged.

When you are admitted to the hospital, wear comfortable clothing and leave important valuables at home or with a trusted companion. If desired, your support person may accompany you while you are admitted.

On your admission day, your clothing and belongings will be locked up and transferred to your hospital room on the ward before your arrival there.

Your family or support person may wait at the hospital during the surgery, at home, or elsewhere near the hospital. Make sure the transplant team knows where they can be contacted.



## Chapter 4 Deceased Donor Kidney Transplantation

A transplant from a non-living donor is called a *deceased donor transplant*. The kidney will be taken from someone who has recently died. You may have to wait many years before you receive a call for a deceased donor transplant. It is important that you try to stay as healthy as possible while waiting for a kidney transplant.

***\*\*\* Please keep in contact with your transplant center. Inform us of:***

- ❖ *Change in contact information*
- ❖ *Change in health status (infections, operations, hospital admissions, etc.)*
- ❖ *Testing being ordered by other physicians that we may not be aware of (for example, heart tests)*

**This chapter describes:**

- I. The waiting list**
- II. How the organs are allocated**
- III. Stress during the waiting period**
- IV. Monitoring your health**
- V. Preparing for the call**
- VI. Receiving the call for a deceased donor transplant**
- VII. The Gift of Life**
  - i. Organ donors**
  - ii. Thanking the donor's family**
  - iii. Donor memorial**

## **I. The Waiting List**

How long you must wait for an organ once you are on the waiting list is difficult to predict. The average wait is estimated to be 5-10 years. The Provincial Active list includes patients from St. Paul's Hospital, BC Children's Hospital and Vancouver General Hospital. Some people are harder to match because of blood type or the presence of antibodies; these individuals wait longer.

When you move closer to the top of the waiting list, you will be informed by your transplant center that you need to submit a blood sample at the beginning of every month. The VGH Immunology Lab will use this blood to mix with any potential donor's blood to see if you are compatible. Testing will also be done for the presence of "cytotoxic antibodies". This test indicates your antibody status to the general population. *In order to remain eligible for any potential deceased donor transplants, you must have your blood drawn in the first week of every month.* You should be responsible for reminding your local lab or dialysis unit each month. You will receive information and a requisition to take to the lab/dialysis unit when you are closer to receiving a transplant.

Occasionally you may need to be put temporarily "on hold" if you develop a medical problem/illness that is not compatible with a successful transplant outcome. We need to ensure that you are in the best physical condition possible when you undergo the transplant surgery to ensure a healthy recovery.

As the waiting time can be long, when you are closer to being transplanted your Transplant Team may request to see you again. At that time, some of the testing you had done as part of your initial assessment may be repeated. This is to ensure you are in optimal shape to receive a transplant.

## **II. How are Organs Allocated**

Currently, kidneys are allocated, within your same blood group, to those people who have been on dialysis the longest. In addition, priority will be given to:

- 1) patients who are unable to dialyze
- 2) patients under the age of 18; and
- 3) patients who have a high antibody level and are at high risk for rejection (if a suitable kidney is identified).

Only patients who are positive for hepatitis C (HCV) will be eligible for hepatitis C positive organs. The wait for HCV positive organs may be shorter than waiting on the regular list.

At the time of transplantation, a cross-match test is performed by the transplant team (immunology department) to ensure that the donated organ is compatible and offers a good chance of success. A negative cross-match means that the recipient does not have antibodies to the donor and therefore is less likely to reject the kidney. A positive crossmatch indicates that the recipient already has antibodies to the donor kidney prior to transplant and will reject the kidney. If there is a positive crossmatch, the surgery will not proceed for that recipient. Organs are not matched by sex, race, or age.

All prospective donors are well tested to ensure a healthy outcome for the recipient. Viruses such as hepatitis and HIV (the virus that causes AIDS) will be tested for. Your transplant team will do everything possible to ensure that you receive an organ with the greatest chance of transplant success.

### **III. Stress During the Waiting Period**

Most people find waiting for a suitable organ very stressful. There are many factors that contribute to added stress at this time.

***Physical disability*** - Due to your illness, you may find yourself unable to do some things that you used to do easily. For example, you may not be able to drive your car or operate machinery if you become too ill. How disabled you are depends on how sick you are. If you have always enjoyed certain physical activities, giving them up can be difficult.

***Financial problems*** - You may find yourself with financial problems or restrictions. The social worker can assist you by ensuring that you are on all the government programs that you qualify for, and can also make appeals to other agencies on your behalf.



***Concern about the donor*** - Some people find themselves concerned that their well-being depends on the death of someone else. It is important to remember that the family members of the donor will receive comfort knowing that something good has come of their loss. Knowledge that the donor's death was not meaningless often helps the family with their grief. Remember, an organ is a gift for life from the donor to you - accept it with joy.

If you require any assistance in dealing with your stress or have any emotional concerns you wish to have help with, please do not hesitate to call the nursing staff or your social worker. These individuals are available to you and want to help make the stress of waiting and living with an illness as manageable as possible.

### **Emotional and Physical Symptoms of Stress**

For some people, the stress experienced from adjusting to the changes in their life may eventually cause physical and emotional symptoms.

#### **Emotional symptoms of stress may include:**

- ❖ anxiety
- ❖ depression
- ❖ loss of emotional control
- ❖ panic and anger

#### **Physical symptoms of stress may include:**

- ❖ nausea
- ❖ difficulty breathing
- ❖ muscle tightness
- ❖ aches and pains
- ❖ shortness of breath
- ❖ palpitations

Worst of all, the build-up of stress can make it harder to get well again.

***Dealing with Stress*** - If you are experiencing symptoms of stress, you are not alone. This is a stressful time in your life. Most people on the waiting list are going through the same things that you are. To help you get through this period in your life, here are some things to think about that others have found useful.

***Know and understand your condition*** - Find out as much as you can about your condition and your medical treatment. The Internet is one way of receiving up to date information. The web site for the BC Transplant Society is [www.transplant.bc.ca](http://www.transplant.bc.ca). Many people find that the more they know, the better able they are to stay in good health until transplantation.

***Discuss your condition with informed people*** - Talking about your condition with informed people, such as members of your transplant team, will help. Excessive worry without expressing your concerns will likely increase your level of anxiety. Talking about your condition will help you know and understand it better.

***Be realistic about your situation*** - A saying to consider is "hope for the best, but prepare for the worst". This may mean preparing a will, or arranging for someone to look after your children in your absence. Many people report that putting their personal affairs in order makes them feel better about facing the future.

***Find a friend for support*** - Do not try to cope with your emotions and feelings alone. Find someone that you can share these feelings with. Discussing your feelings openly with a spouse, sympathetic friend, or support person can help you understand them.

***Continue your normal routine*** - Continue your normal life as long as you can, and be as independent as you can. The less change you allow in your life, the less stress you will feel. Do not give up your usual activities or change your lifestyle unless you have to, or your doctor tells you to.

***Enjoy some private time*** - Sometimes, with everything that is going on, it is difficult to find time for yourself. If you are used to regular time alone, make sure you get it. If you have to, book some time with yourself to do the things *you* want to do, and make sure you do them.

***Learn relaxation techniques*** - staying relaxed is essential to avoiding the physical and emotional symptoms of stress. Learn some techniques for reducing your stress level, such as relaxation and breathing exercises. Physical exercise also reduces stress if you can exercise comfortably, be sure to consult your family doctor.

***\*\*Keep a positive attitude\*\**** - Experience clearly shows that those who can keep a positive mental attitude feel better, respond to treatment better, and have a better survival rate.

***Seek professional help*** - Most people at some point in their lives seek out professional counseling to help them sort out their feelings, or get their life in order. If you would like to speak with a mental health professional, just ask any member of your transplant team. Getting help for psychological or emotional problems is not a sign of weakness, but a sign of healthy self-awareness and a commitment to maintaining a positive attitude towards getting well again.

#### **IV. Monitoring Your Health**

While you are on the waiting list, you will be monitored by either your family doctor, or your specialist, or both. How often you see them will depend on your condition. The more relaxed and healthy you are before the transplant, the faster and easier your recovery will be. Learning ways to better manage your stress may be especially important at this time.

**While you are waiting for your transplant, the following can help you maintain your health:**

- ❖ **Stop smoking!** Quitting smoking will not only help maintain your current health, but can help your new kidney function as well. Speak to your family doctor about smoking cessation help.
- ❖ **Maintain a healthy weight.** Being overweight can increase your risk of developing problems such as diabetes, hypertension, and cardiac disease. People that are overweight are also at higher risk for complications after surgery including wound infections and wound dehiscence (the wound opens up). Speak to your dietician about maintaining a healthy weight.
- ❖ **Remember your yearly check-ups with your family doctor.** This includes Pap tests and mammograms for females, and prostate checks for males.
- ❖ **See your dentist regularly.** Chronic infections in your mouth or teeth can become worse when you are on medications after a transplant.
- ❖ **Take your medications as prescribed.** Your physicians may have prescribed medications for you. These medications are important to maintaining your health! Do not stop taking medications without speaking to your physicians.

## V. Preparing for the Call

Since organs must be transplanted rapidly, and there is no warning when a suitable organ will become available, the transplant team needs to know how to get in touch with you. ***Make sure your transplant center has up to date contact information.*** These phone numbers can include those of neighbors, friends, and family. A cell phone, pager, or an answering machine can be very helpful.

You will need to make plans for travel to Vancouver. Consider who will accompany you and how you will get to the hospital. If you are planning on taking a commercial flight to Vancouver it may be helpful to look into flight schedules before "the call". Other things to consider are ferry schedules if you are coming from the Island and directions to the hospital. Maps of the hospital are available if required. You will need to inform the physician who calls you how long you anticipate you will be in arriving to the hospital.

If you go on holiday, you will have to let your transplant center know where you will be. If you will be staying in the province, generally we can still reach you for a transplant. You will need to let your transplant center know in advance, and provide us with any additional contact information including where you are going and how we can reach you.

If you plan to leave the province, we will need to discuss your plans further with you. We may need to place you temporarily "on hold" if you leave the province.

Once you get the call to come to the hospital, you will not have much time to get ready to leave. On the following page is a checklist for you to use to prepare.

## Checklist: Getting Ready for the Call

	Make arrangements for someone to look after your pets, water your plants, and pick-up your mail while you are in the hospital
	Pack your suitcase in advance and make a list of the items that you will want to add at the last moment (usually things you use every day, like your contact lenses and make-up or shaving supplies).
	Bring clothes that are loose and comfortable (such as a sweat suit) for after the surgery.
	Include a good pair of walking shoes and slippers
	Bring a roll of quarters and loonies for the phone and parking meters. Cellular phones are not allowed in certain areas of the hospital.
	Consider getting a TELUS calling card if you plan on making a lot of long distance calls from the hospital.
	Bring only a small amount of cash.
	With your family, make tentative plans for different times of the day and different days of the week, such as who is going to pick up the kids and who is going to look after the pets.
	Make a list of the people you need to notify and their phone numbers.
	Make a fan-out plan (a plan where you phone two people, they in turn phone two more people, etc., until everyone is phoned). The less you have to do when the call comes, the better.
	Bring a small radio or CD player, a book or two, a box of thank you notes, a pen and your favourite pillow. The more you feel at home and the more you have to do, the quicker the recovery will seem to go.

## VI. Receiving the call for a deceased donor transplant

One day you will receive a call telling you that a suitable organ may have been found for you. The call may come any time of the day or night. A transplant doctor will contact you and ask you how you are feeling and if there are any current problems. ***It is important that you let them know if you are sick or not feeling well in any way.*** They will decide if it is suitable to bring you in for the transplant. If so, they will ask that you come to the Vancouver General Hospital or St. Paul's Hospital emergency admitting department. Let the doctor know how long it will take you to get to the hospital.

**\*\*\*From the moment you receive the call, do not eat or drink anything - this includes gum, candies, even water! Diabetic patients, especially if you are on insulin, should discuss this with the notifying doctor. \*\*\***

If you are coming from within the Vancouver area, leave your pre-packed suitcase behind. Your family or support person can bring it later once you are out of surgery. If you are coming from outside the Vancouver area, bring your pre-packed suitcase with you. Leave valuables behind, such as expensive watches or jewelry, and bring only a small amount of cash and cheques, debit cards and/or credit cards. Maps can be sent, if requested ahead of time, to provided information regarding your transplant centre's location and where to park.

When you arrive at the hospital, go straight to the admitting desk. The doctor who calls you will tell you whether you should report to emergency admitting or non-emergency admitting. Most patients are admitted directly to the renal transplant ward.

Once you are admitted to the ward, preparations for surgery will be made. This will include blood work and possibly dialysis. Much of the testing that you have had previously may be repeated. Blood typing, tissue typing, and virus compatibility will be done. You will meet with members of the transplant team including a surgeon, physician, and anesthetist. The transplant ward nurses and physicians will explain the transplant procedure to you in detail at the time of your admission.

You will be taken to the operating room for the final preparations for transplantation. Family members or your support person may accompany you to the door of the operating room if you and they wish.

Your family or support person may wait at the hospital during the surgery, at home, or elsewhere near the hospital. Make sure the transplant team knows where they can be contacted.

## **VII. The Gift of Life**

Transplantation is only possible because of the gift of life that donors make. Organs for transplantation come from two sources: Deceased donors (from brain dead donors) and living donors, such as family members or friends.

## **Organ donors**

An organ donated from a recently deceased (brain dead) person is called a *deceased donor donation*. These donors are often victims of head injuries or other traumatic injuries. The organs become available suddenly and without warning and must be used within a short time period; therefore, you will only receive a few hours notice of your transplant.

Many donors indicate they want to donate their organs by registering with the *Organ Donor Registry*. Organ Donor Registry Cards are available at the BC Transplant Society and other locations throughout BC. It is important that if you wish to be considered as an organ donor, you must let those close to you know of your wishes. Approximately one of every three organs that could be eligible for transplant is lost due to lack of consent from family.

*Universal Referral* is new legislation in the province of British Columbia, initiated by the British Columbia Transplant Society. All hospitals which are capable of ventilating patients (supporting patients on breathing machines) are required to report all deaths or impending deaths. These calls are then triaged by a central transplant service to determine whether the referral constitutes a potential solid organ or tissue donor. The intention of this legislation is to increase transplantation rates, and to ensure that a particular donor's wishes are honoured.

Deceased donor retrievals are done soon after the brain death of the donor. The body of the donor is maintained, by ventilator, intravenous fluids, and medications, until the organs can be retrieved for transplantation. Deceased donor organs offer an excellent chance for a successful transplant.

## **Thanking the donor's family**

After transplantation, BCT writes a letter to each donor's family expressing thanks and gratitude for the gift of an organ on behalf of all recipients concerned. Nevertheless, we encourage each recipient to thank the donor's family personally. This can be done by writing an anonymous note; BCT will forward this to the donor's family. This not only acknowledges the enormous gratitude felt by each recipient, but additionally helps the donor family immensely in dealing with their grief.

**Donor memorial service**

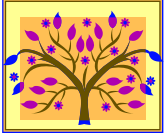
A multi-faith donor memorial service is held in Vancouver and Victoria every six months to acknowledge and pay tribute to the donors for their gift for life. The service is a celebration of that gift, and provides an opportunity to remember the donors and say thank you and goodbye.

All donor families throughout the province are invited to attend, as well as recipients, members of the organ retrieval team, transplant teams, and other medical and support staff involved with organ donations and transplants. It is common for recipients to be asked to speak at the service.

Information regarding dates is available in the Post Transplant Clinic. Please ask your clinic nurse for further information.







## **Chapter 5      Your Transplant**

Once the surgeons have confirmed that the donor organ is suitable for you, you will be given a general anaesthetic to put you to sleep, and the surgery will begin.

**This chapter describes:**

- I.     The transplant surgery**
- II.    After the operation**

### **I.     The Transplant Surgery**

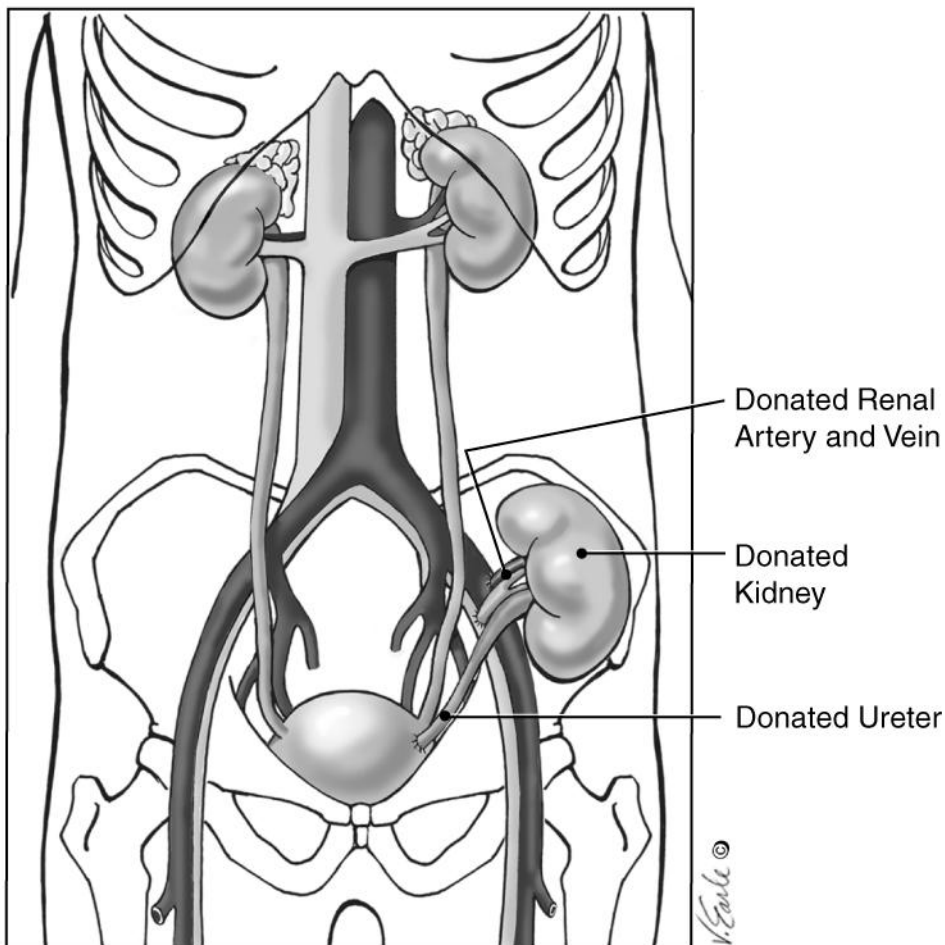
The kidney transplant surgery will take about three hours. During the transplant surgery the donor kidney is placed on either the left or right side in your lower abdomen. Your surgeon will determine which is the most appropriate.

While you are under general anaesthetic, a catheter (foley) will be inserted into your bladder to allow for urinary drainage during and after your operation. In addition, an intravenous line will be started, and a central line (like an intravenous) inserted in your neck in the jugular vein to administer intravenous fluids and medications.

During the operation, the major blood vessels on the side of the new transplanted kidney are prepared, as is your bladder. The transplanted kidney is then placed into your pelvis, the kidney's blood vessels are attached to your pelvic blood vessels, and the new ureter is attached to your bladder. Another drain may be placed along side of the new kidney to allow blood and fluids to be drained away from the surgical site. This drain is brought out through your skin and will be removed after several days, once the amount of drainage decreases.

The muscle layers are then closed and the skin is held together using small metal clips, or staples. These staples will be removed quite painlessly approximately 10 days post operatively. A dressing is applied and will be changed as needed by your nurse on the ward.

After completion of the operation, you will be awakened by the anesthetist and brought to the recovery room. Time spent in the recovery room may vary, and is dependent on how awake you are and the nursing workload in the recovery area as well as on the transplant ward. You will be brought back to the transplant ward after 4-8 hours in the recovery room.



For patients who have had a previous transplant, a transplant nephrectomy (surgical removal) of the first kidney *may* be required prior to placement of a second graft. This will be discussed with you at the time of pre-transplant assessment. Transplant nephrectomies are done before you are activated on the transplant list, or once you have started dialysis. The purpose of this is to make room for your new kidney, and to permit discontinuation of immunosuppressive medications. It is only rarely necessary to remove your native diseased kidneys prior to transplant surgery. Your doctor will tell you if that is necessary.

## **II. After the Operation**

After the operation, you will be taken to the post anaesthetic recovery room (PAR). When you first wake up, you will hear voices, and the sounds of medical equipment around you. For several hours you will be drowsy. You will also notice a bandage on your abdomen, and various tubes, lines, and drains connected to you. If you are having pain from the surgery, your recovery room nurses will administer painkillers, usually through your intravenous lines.

When visitors first see you, you will not look like your normal self. You will have tubes and lines coming from your body, and will be surrounded with equipment. It is not unusual for your face to be swollen from extra fluids (this will disappear in a day or two). You may also temporarily look pale and be cool to the touch, which is partially due to the anaesthetic. Do not be shocked if visitors look startled when they first see you.

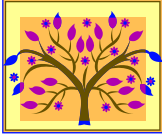
### **Tubes and Lines**

***Endotracheal tube*** - This tube is used to assist your breathing during surgery. It will be connected to a machine called a ventilator to help you breathe with a minimum of effort. This tube is removed in the PAR once you begin to wake up from the anaesthetic.

***Urinary catheter*** - This tube drains your bladder and allows the medical staff to monitor your urine output following surgery. It also allows the bladder to heal by not putting stress on the surgical connection sites. The catheter will be removed in approximately 3-4 days, at the surgeon's request.

***Heart monitor*** - A heart monitor will continuously display your heart rate. An automated blood pressure cuff will also be monitoring your blood pressure.

***Intravenous lines (IV)*** - Intravenous lines in your neck (central venous line), and arms (peripheral IV) will provide you with medications and fluids until you are able to take them by mouth. Most of the IV lines will be removed within 3-5 days, depending on how well you are feeling.



## **Chapter 6      The Road to Recovery**

Once you are out of PAR (post-anesthetic recovery room) and back on the transplant ward, you are on the road to recovery. Step by step you will get your strength back and once again be able to look forward to a normal life.

**This chapter describes:**

- I.          Recovery on the transplant ward**
- II.        Anti-rejection drugs**
- III.       Other medications**
- IV.       Rejection episodes**
- V.         Chronic rejection**
- VI.       Infection**
- VII.      Cancer**
- VIII.     Becoming self-reliant**

### **I. Recovery on the Renal Transplant Unit**

Within a few hours after surgery, if your condition is stable, you will be moved back to the transplant ward. Here your transplant team monitors your progress continually. The nursing staff does hourly vital signs (pulse, temperature, urine output, blood pressure) and physical assessments. After the first 24-hours the frequency of these assessments will decrease. While in hospital, blood work is monitored frequently in the first 24-hours and then every morning before you take your morning medications.

Throughout your recovery, you will be given medications to control any discomfort. It is very important that you have good pain control following surgery so that you can move freely and breathe easily. The nurse will provide pain relief medication for you, but it is important that you ask for it if you are feeling discomfort or anticipate discomfort. You may be given patient controlled analgesia (PCA). This is a pump that will give you a steady dose of pain medication and will also allow you to administer an additional dose by pressing the button. PCA will not allow more than the prescribed dose of medications so there is no threat of being over medicated. The anaesthetist will discuss the options of pain medication with you prior to your surgery.

Your abdominal incision will be covered with a dressing, which the nurse will change daily or as needed. Your incision will be exposed when there is no longer any drainage. Until it has healed properly and the staples are removed, usually about two weeks, you will not be able to have a shower or a bath, just sponge baths. The staples closing the incision are usually removed 10 to 14 days after surgery. If you are discharged from hospital before the staples are removed the Transplant Clinic nurse will remove them.

Your doctor will keep you informed of your progress, with daily visits. If you have any questions, it is a good idea to jot them down so that you are able to remember them when the doctor comes to visit.

### **Physical Exercise**

After surgery, you will feel weak and tired and may be unwilling to exert yourself. However, experience has shown that getting up and about not only makes you feel better, but also reduces the risk of complications, such as pneumonia (infection of your lungs). To get you back on your feet, your nurse and physiotherapist will give you some exercises to do. The goal is to return you to previous level of wellness or better as soon as possible. You will be surprised at how quickly you will start feeling improved, but don't forget that exercise must be balanced with plenty of rest.

### **Breathing Exercises**

While in the hospital, you will do breathing exercises to keep your lungs clear and prevent infection. These exercises include deep breathing and coughing, and must be done five or six times an hour.

## **Diet**

To promote healing and return you to good health, it is important to eat a well-balanced diet. At first you will be given only liquids, such as juices, clear soups and jello. You will progress slowly to small, easily digestible meals and high calorie drinks. As your system returns to normal, you will be able to eat normal food. Most people are back to a normal healthy diet within a week of surgery. Many of the dietary restrictions you faced as a dialysis patient will no longer be applicable, and you may be encouraged to eat foods that were previously on the "no-no list".

Some of the drugs you will be taking may affect your appetite. Some make everything taste the same, while others can make you very hungry. Don't be surprised if you want more or less food than you usually do.

A dietitian will visit to see how much you are eating, assess your blood work and will make changes to your diet so that your body gets all the nutrients you need for a speedy recovery.

## **Length of Stay**

How long you stay on the transplant unit will depend on how fast you are recovering. Everyone recovers at different rates. Most people are discharged within five to seven days. Your doctor and the transplant team will keep you informed of your progress.

## **Emotional Support**

After surgery, you may experience different emotions and feelings than those you experienced before the surgery. Some of these emotions and feelings may be caused by the medications you are taking. Steroids (prednisone) can leave you feeling depressed, irritable, or possibly very excited. Cyclosporine can cause confusion, anxiety, and depression. Many patients have complained of mood swings while taking these drugs.

If you experience mood swings, remember they are probably caused by the drugs and will subside as the dosages are gradually reduced. **Under no circumstances should you change your medication dose yourself.**

Some people also experience anxiety or panic at the prospect of being discharged and going home. Although they have dreamed about going home, leaving the hospital where they feel secure and cared for is frightening.



Some people feel overwhelmed with the emotions they experience, which may be a mix of everything from happiness and excitement to sadness and stress. Medications can exacerbate the severity of these emotions but remember that your feelings are a normal emotional response. Talk to your social worker if you are concerned about any of the emotional responses you may be experiencing.

### **Visitors on the Transplant Unit**

After the operation, your family and close friends will be anxious to see you. The transplant team recognizes the importance of their visits to your recovery. They also know that your family will need support, information, and reassurance. However, the first priority of the transplant team is to ensure that you get enough rest to promote healing.

On the transplant ward, family and close friends are encouraged to visit. Visiting hours are not restricted. However, there may be times when it would be better for your family to stay away. For example, you may be resting, and are better left undisturbed, or a nurse or doctor may be performing a sterile procedure. The nursing staff will try to accommodate you and your family's needs.

\*Children who have recently received *live* vaccinations should not visit. If you are unsure as to what kind of vaccine the child has received, please contact the clinic or physician who administered the vaccine.

\*Visitors with a cold, throat infection, or who feel sick should not visit.

## II. Anti-rejection Drugs

Acute rejection is a common complication for transplant recipients. It occurs because your body's immune system recognizes your transplanted organ as "foreign" and tries to get rid of it. This process is called rejection. Your immune system is your body's defense against infection and disease. If nothing were done to stop the immune system, it would eventually damage or destroy your new organ.

Successful organ transplantation is now possible because of the use of anti-rejection drugs. To try to prevent your immune system from rejecting your new organ, you will be given immunosuppression or anti-rejection drugs (these two names are inter-changeable). The doses of these drugs are carefully measured and monitored so that they prevent rejection, but still allow your immune system to recognize and fight infection.

With the use of these drugs, your chance for a successful organ transplant is excellent. **\*\*You will have to take the anti-rejection medications for as long as you have your transplanted organ. \*\***

Various immunosuppressive drugs are used in combination. When you first start taking anti-rejection drugs, the doses will be high. After the initial period (the first three to six months), as the risk of acute rejection decreases, the doses will be lowered. Usually by the end of your first year after transplant you are taking a considerably lower dose than in the initial period.

Most people take three immunosuppressive drugs. The most commonly used drugs are **tacrolimus or cyclosporine, mycophenolate, and prednisone**. Each drug works in a slightly different way and has different side effects. By taking two or three drugs together, you can be on lower doses of each drug to minimize their side effects, while maintaining an effective defense against rejection and infection.

After you are transplanted, the nurses and the pharmacists on the ward will teach you about your medications, how and when to take them. Initially, nurses will give the medications. Gradually, before your discharge, you will have the responsibility for taking them yourself.

## **Taking Anti-rejection Drugs**

**It is important to take your medications at the same time each day so that you maintain adequate levels of medication in your blood. To ensure that the drugs work properly, you must take them exactly as prescribed.**

**\*\*If you miss doses of your medication, you risk losing your transplanted kidney due to a rejection episode\*\***

*If you miss your dose* and it is less than half the time before your next dose is due, then take the missed dose. If it is more than half the time to your next dose, then skip the missed dose and wait for your next dose. **Do not double your dose.** For example, if you were scheduled to take your medication every 12-hours and you remember to take your medication within 6-hours of the time it was due, then you can take the missed dose. If you have any questions regarding the schedule of your medications or taking missed doses, then make a note of the time and date of the missed dose and inform the transplant team as soon as possible. If you vomit within one hour of taking your medication, repeat the dose.

It is a good idea to record the daily doses of drugs taken, and to bring this record to each clinic visit. The dosage of the anti-rejection drugs are frequently changed in the early phase post-transplant, and many people find it easier to write down the changes to prevent any misunderstanding or medication error.

A description of the medications you may be on and their most common side effects are listed below. Remember that everyone responds differently to medications, so you may experience only some of the side effects or none at all. If you think you are experiencing side effects, talk to your doctor right away.

**\*\*Never change the dose of your drugs or stop taking them unless directed by the transplant team\*\***

**\*\*Remember to always inform your doctor and dentist of the medications you are taking, including over the counter medications\*\***

**\*\*Never run out of medications. Always make sure you have enough\*\***

## **Cyclosporine or Neoral Cyclosporine**

This drug modifies certain white blood cells called *lymphocytes*, which are involved in rejection. To be effective, the drug must stay at a certain level in your blood. If the level is too low, your transplanted organ may be rejected. If the level is too high, your kidneys or liver may be damaged. Usually, any damage is reversible once the drug returns to its proper level.

The level of cyclosporine is measured frequently with a blood test while you are in the hospital, and after discharge during visits to the clinic. You will be instructed to take your morning dose of medication before coming to clinic. You must arrive in clinic and be available to have your blood sample taken at exactly two hours after your dose. This is a precise measurement and can only be varied by 15 minutes before or after the 2-hours post-medication time.

Cyclosporine is available in soft gelatin capsules or in solution form. The capsules are available in 10 mg (white), 25 mg (grey), 50 mg (white), and 100 mg (grey). Each capsule is wrapped in foil, and should be kept in the foil until you need a dose. Swallow the capsules whole. You may take cyclosporine with any drink *except grapefruit juice* (as grapefruit juice will alter the absorption of cyclosporine) unless your physician instructs you otherwise. It is very important that you take cyclosporine with the same drink every time.

Possible side effects of cyclosporine:

- ❖ high blood pressure, and headaches
- ❖ elevated cholesterol
- ❖ increased risk of infection
- ❖ mild hand tremors
- ❖ fine hair growth on the upper body
- ❖ gum tenderness (to prevent problems with your gums, brush and floss your teeth daily, and visit your dentist regularly)
- ❖ sensitivity to hot and cold, flushing
- ❖ vivid dreams

If you notice any of these side effects or any others, tell a member of your transplant team.

## Tacrolimus

Tacrolimus (also known as Prograf® or FK-506) is another anti-rejection drug that acts in much the same way as cyclosporine. Tacrolimus is used in some transplant patients in place of cyclosporine (***tacrolimus and cyclosporine should not be taken together***). Tacrolimus, like cyclosporine, is used with steroids and azathioprine (Imuran®) or MMF (mycophenolate Mofetil) to prevent or treat rejection of the transplant organ.

To be effective, the drug must stay at a certain level in your blood. If the level is too low, your transplanted organ may be rejected. If the level is too high, your kidneys or liver may be damaged. Usually, any damage is reversible once the drug returns to its proper level. The level of tacrolimus is measured frequently with a blood test while you are in the hospital, and after discharge during visits to the clinic. For Tacrolimus you will be instructed to have your blood work done before taking your medications. Taking the blood level at this time is called the "trough" level and should be taken as close to 12 hours after the previous dose as is possible. Monitoring of the 12-hour trough ensures accurate dosing.

Tacrolimus is available in 0.5 mg, 1 mg and 5 mg capsules. The 1 mg capsules are white and oblong with "1 mg" written on the top. The 5 mg capsules are grayish-red and oblong with "5 mg" written on the top.

Possible side effects of tacrolimus (Prograf®):

- ❖ high blood pressure, and headaches
- ❖ diabetes
- ❖ elevated cholesterol
- ❖ increased risk of infection
- ❖ mild hand tremors
- ❖ sensitivity to hot and cold, flushing
- ❖ vivid dreams

Some patients may experience side effects not listed above. If any side effect becomes bothersome or won't go away, contact your doctor, transplant clinic, or pharmacist.

## **Mycophenolate Mofetil**

Mycophenolate (also known as CellCept®) is an anti-rejection drug that suppresses the production of certain white blood cells, which are active in the process of rejection. The drug also suppresses the production of cells that are important in fighting infection. A complete count of blood cells (by a blood test) is done daily while you are in the hospital, and regularly at the clinic once you are discharged. The dosage of mycophenolate is adjusted to keep the blood counts within safe limits.

Mycophenolate has been proven to be very effective in preventing acute rejection during this first year. Mycophenolate is used with either cyclosporine or tacrolimus, and steroids to prevent or treat rejection of the transplanted organ.

Mycophenolate is available as 250 mg (blue/brown) or 500 mg (purple) gelatin capsules. It is important to leave the capsules in the blister pack until you need a dose. When you are ready to take a dose, remove the number of capsules you need. Mycophenolate should be taken on an empty stomach. Swallow the capsules whole.

Make sure your doctor, dentist, and pharmacist are aware of all medications you are taking, including anything you buy off the shelf, such as over-the-counter drugs and herbal or home remedies. Taking antacids at the same time as mycophenolate, for example, may affect the way mycophenolate works for you, so these drugs should not be taken together.

Possible side effects of mycophenolate:

- ❖ low white blood count
- ❖ nausea and vomiting
- ❖ diarrhea
- ❖ loss of appetite
- ❖ weakness
- ❖ swelling of legs and hands
- ❖ infection
- ❖ headaches

Some patients may experience side effects not listed above. If any side effect becomes bothersome or won't go away, contact your doctor, transplant clinic, or pharmacist.

## **Prednisone**

Prednisone is a steroid, similar to one that your body produces normally. It decreases tissue swelling and suppresses rejection. The initial high dose of prednisone is gradually reduced until a low maintenance dose is established. Some patients may not require maintenance steroids. Higher doses of steroids, called "pulse therapy", are used to treat acute rejection.

The most common side effects of prednisone are listed below. Again, remember that everyone responds differently to medications, so you may experience only some of these side effects or none at all.

Possible side effects of Prednisone:

- ❖ stomach upset (should always be taken with food)
- ❖ weight gain and fluid retention
- ❖ bone thinning
- ❖ fullness of the face
- ❖ acne/rash
- ❖ easy bruising
- ❖ joint pain
- ❖ mood swings
- ❖ medication induced diabetes (high blood sugars)
- ❖ infection

If you notice any of these side effects, tell a member of the transplant team. The team will make sure the problem is a side effect of the drug, and not a sign of rejection or another medical problem.

## **III. Other Medications**

The medications in the previous section are to keep your body from fighting your new transplant. You will be on other medications as well, including:

- ❖ medications that protect you from infection (see section IV.)
- ❖ medications to deal with the problems (side effects) caused by the anti-rejection medications
- ❖ any other medications required for unrelated medical conditions (for example, some people take thyroid medications).

Following surgery, you will begin taking 8 to 10 drugs, which may include:

- ❖ Cyclosporine or Tacrolimus
- ❖ Mycophenolate
- ❖ Prednisone
- ❖ Anti-viral drug (Valganciclovir or Ganciclovir)
- ❖ Anti-fungal drug (Nystatin or Fluconazole)
- ❖ Anti-bacterial drug (Cotrimoxazole or Septra)
- ❖ Anti-hypertensive drug (Nifedipine for example)
- ❖ Anti-ulcer drug (Ranitidine or Losec)
- ❖ Vitamins and Minerals (Centrum forte, calcium, and magnesium)

All these medications are important to your health after the transplant. As with your anti-rejection medications, **do not stop or change any of your medications until you speak to your doctor.** Tell your transplant team if you think you are having any side-effects from medications.

Once you have adequately recovered, you are expected to participate in a self-medication program. Nursing and pharmacy staff will review each medication with you. Initially, your nurses will give the drugs, but before you are discharged, they will teach you what each drug is for, how and when to take it, and possible side effects.

#### **IV. Rejection Episodes**

Approximately 1/5<sup>th</sup> of patients will experience an episode of rejection. It is referred to as an *episode* of rejection because it is usually a temporary, reversible event. It is most likely to occur in the first six months of having your new organ, but it can happen at any time as long as you have the organ.

Rejection may occur even if you have been taking your medications faithfully. While you may find this thought unsettling, it is a common occurrence. In most cases, with early detection and treatment, the transplant team should have no problem reversing the rejection completely. The best way to fight rejection is to stop it before it starts, and to recognize it and treat it early.

**\*\*You can work at preventing rejection by taking your medications faithfully and getting your blood work done as required\*\***



## Signs of Rejection

Many rejection episodes are mild and do not have symptoms. These episodes are only found out with blood tests. Early identification and treatment of symptoms are important in successfully reversing rejection. Your doctor in the transplant clinic may suspect a rejection episode only because the creatinine has risen slightly above the previous level. It is therefore critical that you have all lab testing done as ordered.

On the other hand, some individuals may feel symptoms of the rejection episode. To ensure that the rejection is treated quickly, watch for any of the following warning symptoms:

- ❖ decreased urine output
- ❖ weight gain of one kilogram (2.2 pounds) per day, or more, sometimes with swelling of the ankles
- ❖ increased temperature/fever
- ❖ tenderness over transplant site
- ❖ shortness of breath while doing normal activities
- ❖ In general, a feeling of unwellness

**\*\*If you experience any of these symptoms, report it to your transplant team immediately\*\***

## Treatment of Rejection

Rejection is usually determined by a renal biopsy done under guided ultrasound. This will confirm rejection or indicate the status of the transplanted kidney. Under local anesthetic a small piece of kidney tissue is removed with a biopsy needle and examined.

When rejection is detected, it must be treated immediately. Treatment usually involves high doses of a steroid, Solu-Medrol, which can be given intravenously (through an IV, called "pulse therapy") or by an increase in prednisone tablets taken orally. In most cases, this will reverse the rejection. The intravenous medication may be given in hospital or in the transplant clinic.

Blood work, especially the serum creatinine, is the best indicator of kidney function. You will have regular blood work done to monitor your creatinine levels to assess the effectiveness of the "pulse therapy".

If high doses of steroids are not effective, there are other treatment options that are very effective. However, these drugs are more potent, and therefore may carry more risk of infection or long-term malignancy with their use. This next level of immunosuppressive therapy includes such agents as OKT3, and ATG or ALG.

OKT3 is a medication, which blocks the function of the immune cells that are responsible for rejecting the organ. It belongs to a class of medication called monoclonal antibody and is very effective against lymphocytes. It has to be given intravenously. A typical course would last 7 to 10 days. OKT3 can cause severe flu-like symptoms during the initial two or three doses. You must be admitted to hospital for the initial doses and given medication to help minimize these symptoms. Subsequent doses can be administered on an outpatient basis.

ATG (anti-thymocyte globulin) belongs to a polyclonal class of antibody. It works much the same way as OKT3 and is also very effective. It has to be given by a central intravenous line in the neck, which means that you will be in hospital for the duration of the treatment. Total treatment times are similar to OKT3.

Because these drugs are more potent immunosuppressives, they carry an increased risk of infection, in particular, viral infections. It is common to receive anti-viral medication at the same time as these antibody therapies.

## **V. Chronic Allograft Nephropathy (or Chronic Rejection)**

Some transplant recipients may experience CAN (chronic allograft nephropathy), a condition that most often occurs over a long period of time. Ongoing CAN slowly damages the transplanted organ. Most often CAN has no symptoms. Your doctor may suspect this condition after noting a slow but steady rise in creatinine over the years.

CAN is diagnosed by kidney biopsy. We don't fully understand the causes of CAN, but possible explanations include very low and undetectable levels of acute rejection (so-called sub-clinical rejection), some of the medications used to prevent acute rejection in the first place (such as cyclosporine), and even the causes of your initial kidney failure that may still be present. Unfortunately, unlike acute rejection, it is not possible to reverse the damage, and there is no proven therapy.

There is intense interest in transplantation now in understanding factors that are important in the development of CAN, and clinical trials are underway to determine whether effective treatment strategies exist. As with acute rejection, CAN can occur despite taking your medication regularly. You may need to change to a different anti-rejection drug.

## **VI. Infection**

A possible side effect of anti-rejection drugs is an increase in infections. While suppression of the immune system is necessary to prevent organ rejection, it weakens the body's ability to fight off infections. Fortunately, there are ways of reducing the risk of infection while still maintaining adequate defenses against rejection.

The risk of contracting an infection is higher during the first few months following a transplant when your doses of anti-rejection drugs are high. As the doses fall, the risk of infection falls. As with rejection, the key to fighting an infection is to prevent it, identify it early, and treat it quickly.

### **Preventing Infection**

The best way to prevent an infection is by avoiding close contact with people who may be ill. Most viruses, bacteria, and fungi are passed from person to person in tiny water droplets and may be transferred simply by shaking hands. Someone sneezing or coughing is sending out droplets, which you might breathe in, or transfer to your mouth or other mucous membrane (such as your eyes) with your hands.

During the first few months following your transplant, you must be diligent in avoiding infections. This may mean having to avoid normal close contact with family members or your spouse if they are sick.

You may not be able to prevent all infections, but you can certainly reduce the risk by washing your hands regularly and avoiding putting your fingers in your mouth or touching your eyes. Family and friends with infections should also wash their hands before touching you.

Avoid:

- ❖ people with colds or infections
- ❖ crowded, poorly ventilated, smoke-filled rooms
- ❖ public transportation, especially at rush hours
- ❖ public whirlpools
- ❖ activities that may cause breaks in the skin (when gardening, for example, wear gloves)
- ❖ changing cat and bird litter

It also helps to alert your co-workers to the fact that you are on immunosuppressants. You will find that people are remarkably considerate when they know the situation. After the transplant, you may be taking medications to prevent commonly occurring infections.

### **Signs of Infection**

Early detection is essential to the successful treatment of infection; therefore it is important to report any symptoms immediately to your transplant team.

Symptoms of infections are:

- ❖ A temperature above 37.5° C (99° F); if your temperature is high, take it a second time in one hour, before calling
- ❖ Coughing up green or yellowish sputum, or a dry cough
- ❖ A burning or stinging feeling when you urinate, or a pink tinge to the urine
- ❖ Sores anywhere on the body, including cold sores
- ❖ Any redness, swelling, discharge, or pain around your incision, or around any cut or scrape
- ❖ Nausea, vomiting, diarrhea
- ❖ Neck stiffness accompanied by headache

**\*\*Remember, if you have any of these symptoms;  
report them to your transplant team immediately\*\***

### **Treatment of Infection**

Just as with rejection, the keys to fighting infection are first, to prevent it, and second, to detect it early and treat it quickly. A wide variety of viruses, bacteria, and fungi can cause infections, and a wide variety of drugs are used to combat them. The drug you will be given will depend on the type of infection and its location. You may receive more than one drug. You will be given more information on a drug when it is prescribed.

## **VII. Cancer**

Certain types of cancer, particularly skin and lymph node cancer (lymphoma), and cervical cancer for women, are possible complications of the long-term use of anti-rejection drugs. These drugs, while altering your body's immune system to prevent rejection, may leave you more vulnerable to other diseases, including some cancers. The initial approach for treatment of lymphoma is to reduce the doses of the anti-rejection drugs to allow the immune system to fight off the cancer. Any new skin lesion or change to a mole should be reported to your doctor and transplant clinic nurse. Cervical cancer can be detected with regular Pap smears and treated very effectively if diagnosed early.

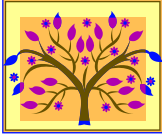
## **VIII. Becoming Self-reliant**

### **Monitoring Your Own Health**

The last leg of your trip on the road to recovery is becoming self-reliant again. While you are on the transplant ward, the transplant team will teach you how to monitor your own health and take your own medications. Pay attention to what your body is telling you and report any problems to the transplant team.

### **Preparing for Discharge**

Your family and friends are an important part of your support system. We strongly encourage you to have at least one person participate in learning about monitoring your health and taking your medications. Make arrangements with your nurse for training of your support person. Before leaving the ward, you will meet a post-transplant nurse and may be given a tour of the transplant clinic. You will be followed there regularly for check-ups and blood work. The visit will give you an opportunity to meet the staff and become familiar with the routine of future clinic appointments.



## **Chapter 7 Adjusting to your New Life**

After your transplant, you will want to return to your normal life as quickly as possible. While the transition from hospital to home is normally a happy time, there are many adjustments to make. At first it may be difficult to return to a normal life as so much time is taken up monitoring your health and taking medications, but with time, these tasks become easier.

A common reaction to going home is to feel stressed. One important way of minimizing stress is to make sure you feel confident looking after yourself and monitoring your own health, so this chapter focuses on:

- I. Monitoring your health**
- II. Transplant clinic visits**
- III. Medications and other costs**
- IV. Routine health care**
- V. Guidelines for healthy living**
- VI. Driving**
- VII. Traveling**
- VIII. Sexual activity**
- IX. Community resources**
- X. When to call the transplant team**

## I. Monitoring your health

As a transplant recipient, it is extremely important that you monitor yourself for any signs or symptoms of rejection or infection. As noted in an earlier chapter, often there may be no indication that you are experiencing an episode of acute rejection, and it is only from the routine testing of your blood in the clinic that the transplant team becomes aware of this possibility. Nevertheless, you may notice a discomfort over your graft, a decrease in the amount of urine being passed, an increase in your weight, or the presence of new swelling of your ankles (edema). These changes should be reported promptly to the transplant team.

**Blood Pressure:** Blood pressure reflects your kidney function and your heart's output and ability to pump, the volume of fluid circulating in your system. Many people prefer to monitor their blood pressures at home, in which case you can buy your own blood pressure measuring device. Your social worker or nurse will advise you where to buy one and the nurse will show you how to properly use it.

**Pulse:** Your pulse tells you how fast your heart is beating. Count the rate for 15 seconds, then multiply by four to calculate the beats per minute.

**Weight:** Weigh yourself at the same time every day. Empty your bladder first. Notify your transplant team if you gain more than one kilogram (2.2 lb.) in one day. You may be retaining water, which may be a symptom of rejection.

**Temperature:** An increase in body temperature may be a symptom of infection or rejection. Initially, you may want to check your temperature daily, and any time you feel hot or unwell. You can buy a thermometer at any drug store. Make sure you get one that measures in Celsius.

Wait 10 minutes after eating or drinking anything hot or cold before taking your temperature. If the reading is above 37.5° C, take it again in one hour. If your temperature is still above 37.5° C, report it immediately.

## II. Transplant Clinic Visits

The purpose of clinic visits is to closely monitor your progress so that any problems or complications can be treated promptly. You will receive more information about the transplant clinic before you leave the transplant ward.

After you are discharged from the hospital, you must visit the Transplant Clinic twice a week for the first four to six weeks. After that, you will probably need to visit less often. In general, by six months, most people come to clinic once a month, unless there are problems. For those individuals not from Vancouver, you may transfer care to one of the six regional clinics after eight to twelve weeks, provided that there have been no complications.

How frequently you visit the clinics will depend on how well you are doing. Some people recover faster than others and have fewer complications. Your doctor will advise you on your progress.

Your clinic visits may include:

- ❖ blood work
- ❖ a visit with the clinic nurse
- ❖ an examination by your transplant physician
- ❖ meetings with other transplant team members

The clinic staff will monitor your test results and notify you by telephone of any concerns when appropriate.

**If you live outside of the Lower Mainland, you will need to *find and pay for a place to stay in Vancouver for approximately the first two to three months.*** You will have to arrange your own transportation to and from the clinic. If you anticipate that you will need help with accommodation or transportation, it is important that you talk to your social worker well in advance of transplant surgery. See chapters 3 and 4 regarding pre transplant arrangements.



### **III. Medication and Other Costs**

The anti-rejection drugs you will be prescribed are available free of charge from the Transplant Outpatient Pharmacy. You must purchase other non-immunosuppressive drugs at your local pharmacy. Keep your receipts so you can apply for reimbursement of a portion of these costs through BC's Pharmacare Plan. Application forms are available from your pharmacy. For more information, talk to your pharmacist.

During the first three to six months, you may also be taking drugs to prevent infections, treat high blood pressure, or help with acid reflux, so the total cost of your medications will be quite high. Once you stop taking some of these drugs, the cost will come down significantly. Talk to your transplant team and other recipients about the best and cheapest places to buy your drugs.

Besides medications, there are other expenses that you may incur after your transplant, including:

- ❖ Accommodation in Vancouver before you can return to your community
- ❖ travel to and from the Transplant Clinic
- ❖ health monitoring equipment and supplies, such as blood pressure device, weight scale, and thermometer
- ❖ medic alert bracelet or necklace
- ❖ other supplies if required (gauze, tape, cleaning solutions)

### **IV. Routine Health Care**

Even though you will be making regular visits to the Transplant Clinic, you should continue to have yearly medical check-ups with your family doctor. For women, the check-ups should include a breast exam and a Pap smear. Women should continue to do monthly breast self-examinations at home. For men, your annual check-up should include a prostate exam.

For colds, flus, and other illnesses that are not related to your transplant, continue to see your family doctor. Before you take any prescription or non-prescription drugs, check with the transplant clinic first. Some drugs that your doctor may not be aware of can react with your anti-rejection drugs.

***Medic-alert bracelet or necklace*** - Wear a medic-alert bracelet or necklace after your transplant. In an emergency, this will identify you as a transplant recipient who is taking anti-rejection drugs.

***Dental care*** - After the transplant, when you are taking anti-rejection drugs, you will be more susceptible to oral infections. Visit your dentist every six months for an examination and cleaning. When booking an appointment, make sure your dentist knows that you are a transplant patient and are taking anti-rejection drugs. Before any dental work, including cleaning, you may need to take antibiotics to prevent possible infections. It is important to maintain oral hygiene, which includes daily brushing and flossing.

***Immunizations*** - Make sure you continue to get your regular vaccinations for tetanus. When getting any other vaccinations, make sure you are not getting a *live* vaccine (some live vaccines are polio, measles, BCG, small pox, and yellow fever). This is not a good idea for transplant recipients. **Check with transplant clinic before getting any shots.**

If you are around children who may have recently received live vaccinations, avoid coming in close contact with their body fluids. This means avoid kissing children or changing their diapers for six weeks after vaccination. Contact the transplant clinic for more information on vaccinations.

Flu shots are a good idea, although they may not be effective if given in the first six months after transplantation. This is because the immunosuppressive medications may block effective immunization. Hepatitis B vaccination is important prior to transplantation. We recommend that renal patients receive hepatitis B vaccination either before they start dialysis or while on dialysis. Contact your transplant clinic for more information.

***Eye Examination*** - Some of your medications may cause your vision to change. It is usually a good idea, however, to put off changing your prescription for at least six months. Sometimes your vision will go back to normal once the dosages of some of your medications are reduced. If you have any changes in vision after transplant, it is important to report this to your transplant team, as in some instances, this may suggest an infectious problem. The transplant team can refer you to an ophthalmologist quickly if necessary.

## V. Guidelines for Healthy Living

***Do not smoke*** - Smoking is bad for anyone's health, and especially bad for transplant recipients. Because you are taking anti-rejection drugs, you have a higher risk of getting lung infections or cancer. Second-hand smoke is also harmful, so stay out of smoky areas. We know that those who smoke have reduced survival of the kidney transplant compared to those who don't smoke. Wherever possible, we encourage individuals to stop smoking prior to transplantation.

There are now many strategies available to help with smoking cessation. These include self-help groups, hypnosis, the nicotine patch (which replaces inhaled nicotine and all the toxins involved in cigarette smoke with a pure form of nicotine), and drugs, which work on reducing craving (Zyban or Wellbutrin). Often a combination approach is essential if you are to succeed. Remember, the transplant team is sincere in wanting you to enjoy the benefits of your newfound health, and will assist you in trying to quit smoking. It may take several tries before you are able to quit smoking, so don't be discouraged if you don't succeed on your first attempt.

***Alcohol consumption is permitted, but the key is to drink in moderation.*** You should not drink for the first six months following transplantation. After six months, you may enjoy the occasional alcoholic beverage. **If alcohol abuse was a major health issue identified prior to transplantation and you signed a contract of abstinence** with the transplant team prior to surgery, then you must continue to follow your contract and not drink. Moderate drinking is no more than one drink per day. One drink can be either 4 oz of wine, 8 oz of beer, or 1 oz of hard liquor. Never drink alcohol with your medications, particularly with cyclosporine. Never have a drink within one hour before or after taking cyclosporine. Alcohol affects the absorption of cyclosporine.

***Eat healthy foods*** - Try and keep your weight within the normal range for your height and build. It is easy to gain weight after transplantation. This is related to several factors. Firstly, most of the food restrictions in place prior to transplant are lifted, and many people want to try all the foods they were forbidden for so long. Secondly, with the restoration of good health, most people find that their appetites have vastly improved, and the amount of food consumed increases. Thirdly, prednisone may have an effect to increase appetite.

Many people struggle with unwanted weight gain after transplantation. This is especially true for those individuals who were overweight prior to transplantation. The dietitian in the transplant clinic can assist you should there be any concerns regarding excessive weight gain, or weight loss.

Try to reduce the amount of fat, particularly animal fat and cholesterol, in your diet to protect your coronary arteries from fatty build-up. Try to restrict the amount of sodium in your diet so you will not retain water. Avoid potato chips, pretzels, and other salty foods. Do not add salt to food at the table and try to use as little as possible in cooking. The transplant dietitian will review your diet with you after the transplant and monitor your progress during clinic visits.

***Wear Sunscreen*** - Some of your medications may make your skin more sensitive to the sun and can increase your risk of a sunburn or skin cancer. It is a good idea to use a sunscreen whenever you are outside, but particularly if you are in a tropical climate, near water, on snow, or at a high elevation. Also limit the length of time you spend in the sun.

Transplant recipients are at greater risk of developing skin cancer compared to those who have never been on immunosuppressive drugs. Make sure you report any new lumps, bumps, or moles to your transplant team. The best sunscreens are those classified as SPF (sun protection factor) 15 or higher. Make sure it is waterproof so it does not come off when you go in the water or sweat.

## VI. Driving

Check with your transplant physician before you start driving again. Generally, you will be able to drive once your incision is healed - usually about six to eight weeks after your transplant. But before you drive, think about how you feel, particularly your:

- ❖ vision and hearing
- ❖ physical coordination and reaction time
- ❖ muscle strength, endurance, and comfort with turning in your seat
- ❖ general awareness and judgment
- ❖ memory of physical surroundings

Wearing a seat belt over your incision may bother you initially. Pad the area with a small blanket or pillow.

## VII. Travelling

Travelling and taking holidays are some of the many bonuses of having a transplant. Once your transplant physician has told you that your condition has stabilized and you do not need frequent blood work, you can start planning. There are few limitations on where you can safely travel.

**Before leaving, however, notify the clinic first.** The clinic will give you a letter listing your current medications (sometimes useful when crossing borders), recent blood work results, and phone numbers of the transplant clinic where you can contact your transplant physicians, and the nearest transplant centre in the area you are travelling.

***Travel health insurance/cancellation insurance*** - Because the cost of medical services can be high outside Canada, it is a good idea to carry travel health insurance. It is also a good idea to get cancellation insurance on your flights and bookings in case you suddenly have to change your plans.

***Medications*** - Keep all medications in their original containers when travelling so that the drug name is clearly marked. This is very important when crossing borders. Carry twice the amount of anti-rejection drugs that you will need.

**Keep half with you at all times** and put the other half in your luggage. That way, even if your luggage or handbag is stolen or lost, you will have enough medications to get you through the trip.

**Bloodwork** - If you are going to be away for more than two weeks, you may need some blood work done while you are away. Since you will have to pay for it yourself, only the minimum tests are usually needed. Check with your transplant physicians.

**Sunscreens** - See the above section on sunscreen. Using sunscreen is even more important if you are travelling to sunny destinations.

**Immunizations** - Check with you local community health agency and transplant physicians to see if you will need any immunizations for the places you intend to visits.

## **VIII. Sexual Activity**

As a general rule, sex takes about as much energy as climbing two flights of stairs. For several weeks after the transplant avoid putting too much strain on your incision. Let your comfort level be your guide. If you have any questions about sexual activity, or questions about family planning, discuss these with your doctor or clinic nurse. You may need to discuss your choice of contraceptives with your doctor. Oral contraceptives (the pill) may interfere with cyclosporine absorption, and are generally not recommended.

### **Pregnancy**

Pregnancy should be considered only after one and a half to two years post transplant. This is to ensure that kidney function and general medical health are optimum. Please discuss with your nephrologist if pregnancy is in your plans, as some of the medications (both immunosuppressive and non-immunosuppressive) may need to be changed prior to conception. Men who contemplate fathering children should also discuss this with the transplant physician or nurse to assure that no change in medication is required.

## **IX. Community Resources**

If you need any help at home before or after the transplant, there are community resources available. Your transplant team can assess your needs and arrange for help. Subject to eligibility, resources may be available for:

- ❖ physiotherapy and/or occupational therapy
- ❖ nursing care at home
- ❖ looking after your children
- ❖ help with cooking and house cleaning
- ❖ help with transportation

Please feel free to discuss your eligibility for the above resources with your social worker

## **X. When to Call the Transplant Team**

Call the clinic immediately for any problems or concerns related to your transplant or anti-rejection drugs. The transplant team is particularly interested in symptoms of rejection or infection, so you should report any of the following:

- ❖ weight gain of more than one kilogram (2.2 pounds) in one day
- ❖ increase/decrease in blood pressure of more than 20 mmHg from your normal level
- ❖ swelling of the body tissues due to salt and water retention (edema)
- ❖ shortness of breath
- ❖ body temperature of more than 37.5° C more than one hour
- ❖ loss of appetite or nausea
- ❖ decrease in urine out-put
- ❖ tenderness over transplant graft site

Remember, it is better to call and have it turn out to be nothing, than not to call and have something significant go untreated.

Please see the contact numbers on the next page.

**For St. Paul's Hospital Transplant Recipients:**

During regular clinic hours, contact the transplant clinic at **604-806-9016**.

Outside of clinic hours and on weekends, you can call the **St Paul's Hospital Main Switchboard** at **604-682-2344** and ask the operator to page the **Nephrologist on call**.

**For Vancouver General Hospital Transplant Recipients:**

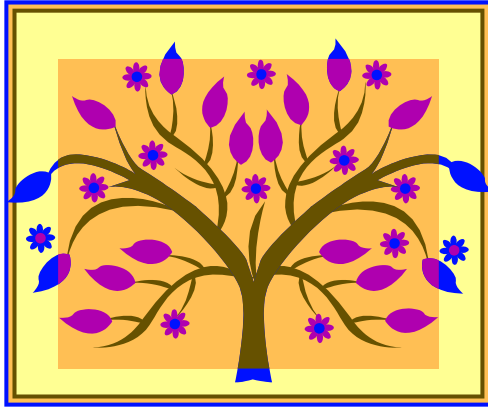
During regular clinic hours, contact the transplant clinic at **604-875-4439**.

Outside of clinic hours and on weekends, please contact the **BC Transplant answering service** at **604-877-2240** and ask for the **Nephrologist on call**.









*Providence*  
HEALTH CARE  
How you want to be treated.

[www.transplant.bc.ca](http://www.transplant.bc.ca)