



BRIGHAM AND
WOMEN'S HOSPITAL

Brigham and Women's Kidney Transplant Program

Pre-Transplant Handbook

Members of the Kidney Transplant Team

DAYTIME: Monday – Friday, 8:00a – 5:00p

Call the nurse coordinator first at **617.732.6123**, if you get the answering machine, please leave a message and it will be returned ASAP.

**EVENINGS, WEEKENDS, HOLIDAYS ONLY
(FOR EMERGENCIES ONLY)**

Call the Page Operator at 617.732.6660 and ask for the “Renal Fellow On-Call”

Transplant Surgeons

Tel: 617.732.6446

Fax: 617.582.6167

Dr. Stefan G. Tullius, Program/Surgical Director
Dr. Sayeed Malek, Clinical Director
Dr. Sanjaya Kumar, Transplant & Urology

Pre-Transplant Nurse Coordinators

Tel: 617.732.6866

Fax: 617.582.6167

Karen Bessette, RN
Sheila Patterson, RN
Michelle Scala, RN

Living Donor Coordinator

Tel: 617.732.8683

Fax: 617.582.6167

Kristen Pelletier, RN

Transplant Financial Coordinator

Tel: 617.525.7415

Fax: 617.582.6167

Valerie Moals-Phillips

Transplant Nephrologists

Tel: 617.732.6383

Fax: 617.975.0840

Dr. Anil Chandraker, Medical Director
Dr. Reza Abdi
Dr. Edgar Milford
Dr. Leo Riella
Dr. Jamil Azzi
Dr. Andrew Siedlecki
Dr. Jae H. Chang

Transplant Social Workers

Fax: 617.582.6167

Barbara Levine, LICSW

Tel: 617.732.7882

Annette Pimenta, LICSW

Tel: 617.732.6480

Transplant Pharmacist

Tel: 617.732.7658

Fax: 617-732-7507

Steven Gabardi, Pharm. D.

TABLE OF CONTENTS

Section 1	Introduction to Kidney Transplant
Section 2	Before Your Kidney Transplant
Section 3	At the Time of Your Transplant

HOW TO USE THIS BOOK:

This handbook will provide you with the information you need from the time you are first assessed for transplant, through your hospital stay, clinic visits, and years into the future. We understand that all this information can be overwhelming so please take your time as you review this booklet. Read the sections that are relevant to your **current** stage of care first. Don't worry; you will have years to become an expert on this information, so continue to use this booklet as a reference. ***Please remember to bring this book with you every time you come to the hospital or to see your transplant physicians and nurse.***

Section 1: Introduction to Kidney Transplant

- 1.1 Welcome
- 1.2 Resources
- 1.3 Social Worker and Financial Coordinator
- 1.4 Other Useful Information

Dear Patient or Family Member,

Welcome to the BWH Kidney Transplantation Program. We encourage you to read this book frequently – both before and after your transplant. The more educated you and your family are about kidney transplantation, the better!

You will find more useful information on our website at:

www.brighamandwomens.org/Departments_and_Services/surgery/services/transplantsurgery/Default.aspx. And, of course, our team of transplant physicians, physician assistants, transplant nurses, transplant pharmacists and transplant social workers are happy to answer questions you may have about any aspect of the transplant process.

In this book, you will find information about many useful topics such as:

- how you will be evaluated for transplant
- the types of kidney transplants available
- the transplant surgery procedure itself
- the medications required after transplant to prevent rejection
- how to follow-up in clinic after discharge
- who to contact for any medical issues after discharge
- when you can return to work and normal activities
- healthy eating after transplant

Kidney transplantation is ‘a gift of life’ and we hope that this booklet helps enable you to really enjoy this gift.

Sincerely,

***The Kidney Transplant Team at
Brigham and Women’s Hospital***

Kidney Disease and Transplant Information Web Resources:

- **New England Organ Bank (NEOB):** www.neob.org – Federally designated organ procurement organization for all, or part of, six New England states, that provides support to families involved in donation process, and education to health care professionals, as well as to the public.
 - **United Network for Organ Sharing (UNOS):** www.unos.org – Private, non-profit organization that manages the nation’s organ transplant system under contract of the Federal Government.
-
- **EMMI:** Online educational program that will help you prepare for your procedure and manage your care: <http://www.emmisolutions.com/> (this program is currently available in the waiting area of the Schuster Transplant Center)
 - **American Association of Kidney Patients:** 800-749-2257. www.aakp.org – Provides education, advocacy, and builds communication amongst kidney patients.
 - **American Diabetes Association:** www.diabetes.org – Diabetes news, research, and other information.
 - **Organ Procurement and Transplantation Network:** <http://optn.transplant.hrsa.gov/> - Monitors transplant programs for efficacy of the United States organ transplant system. Scientific Registry statistics for transplant programs available at this site.
 - **Donate Life:** <http://donatelifenet.net/> - Official website of the Donate Life initiative, gives information on understanding donation, stories of hope, and getting involved in the process of donation.
 - **National Kidney and Urologic Diseases Information:** <http://kidney.niddk.nih.gov/> - Current topics in kidney research.
 - **National Kidney Registry:** <http://www.kidneyregistry.org> – Information about how the swap program works. The mission of NKR is “to save and improve the lives of people facing kidney failure by increasing the quality, speed, and number of living donor transplants in the world.”
 - **National Kidney Foundation:** 800-542-4001. www.kidney.org – Leading health organization dedicated to fighting kidney disease.
 - New England branch of the National Kidney Foundation: www.kidneyhealth.org
 - **The Federal Government Organ Donation:** <http://www.organdonor.gov/index.html> - Information on enrolling, donating, donor/recipient matching, receiving an organ, transplant waitlists, planning finances, allocation of all organs, etc.
 - **Kidney Transplant/Dialysis Association:** 781-641-4000. www.ktda.org – An all-volunteer, patient-run, non-profit organization dedicated to providing financial aid, information and emotional support to chronic renal disease patients and their families.
 - **The Scientific Registry of Transplant Recipients (SRTR):** www.srtr.org – A National database of transplantation statistics.
 - **TransWeb:** www.transweb.org – TransWeb’s mission is to provide information about donation and transplantation in order to improve organ and tissue procurement efforts worldwide, as well as to provide transplant patients and families with information specifically dealing with transplant-related issues and concerns.

Section 1: Introduction to Kidney Transplant

1.3 Social Worker and Financial Coordinator

Your Transplant Social Worker can be helpful by providing information, referral or counseling on a wide range of issues that you and your family may face. The following is a partial list of topics, services, entitlements and issues that the social worker can help you with. In some instances, the Transplant Financial Coordinator can also be helpful. Please feel free to contact the social worker, or financial coordinator, where indicated for further information or assistance in any of these areas. You will be seen by a social worker before, at the time of, and after your kidney transplant.

Some of the issues that your Social Worker can assist with are:

Adherence/Compliance with medication regimen:

This refers to your ability to take your medications as directed and follow your caregivers' recommendations and instructions very carefully.

As a transplant patient you **cannot** take your health for granted. We expect you to be proactive, to take responsibility for educating yourself about your kidney and what you can do to keep yourself healthy. Research tells us that non-compliance with medication dosing and other instructions is the most preventable cause of rejection, and a major contributor to transplant failure. **Please speak to your transplant caregivers if you believe you are facing barriers to good compliance---whether these barriers seem within, or outside of, your control. Your social worker and the rest of the transplant team will work with you and your family to help you overcome these barriers.**

Psychological Services:

Patients may find the transplant process very challenging, both physically and psychologically. Depression and/or anxiety can develop or worsen at this time. Some medications can worsen psychological symptoms. We want you and your family to know that psychological help and support is available from your transplant medical providers, as well as from the Social Worker, the Renal Transplant Psychiatrist, or through referral to a mental health clinician in your area. Please call your social worker or speak to the transplant team **early/as soon** as possible if problems start to occur.

Insurance and Coordination of Benefits:

If there are any changes AT ALL in your insurance, it is important that you contact either your social worker or transplant financial coordinator **immediately**. Lack of insurance coverage carries the risk of inability to pay for your medications, and taking your medications is crucial to the success of transplant. *The transplant office cannot supply medications for you – this needs to be your responsibility.* The financial coordinator and/or social worker may be able to assist you in finding temporary funding sources, if and when available.

“Coordination of Benefits” refers to how your insurances work together to pay for your care. It is very important that you keep the transplant financial coordinator and social worker informed and each of your insurers informed, whenever you add or lose coverage to make sure proper billing occurs in the proper sequence (primary vs. secondary coverage).

Dental Health:

If you, your doctors, or your Transplant Coordinator feels that a pre-transplant dental examination or treatment is indicated, the social worker can direct you to reduced cost dental care or can provide documentation for MassHealth for prior authorization, if needed.

Disability Income Programs:

Social Security Disability (SSDI), Supplemental Security Disability (SSI), Emergency assistance (EAEDC), job related disability plans, or private disability coverage all offer income if you meet the eligibility criteria. In addition to meeting disability criteria, some programs consider work history, income and asset limits, and some have waiting periods and time limits. The social worker can explain criteria and how to apply for the appropriate program(s) for you.

Donor Bills:

Your donors should not receive bills for their pre-transplant work-up or hospital stay. If they do, please forward the bills to the Transplant Finance Coordinator, Valerie Moals-Phillips: 617-525-7415; fax: 617-582-6167.

Family Medical Leave Act (FMLA): Social workers cannot fill this out, as it requires medical documentation; needs to go to the Transplant Nurse Coordinator or Physician.

Provides up to 12 weeks of unpaid leave and job security for most employees who are ill. Family member/caregivers also may qualify. Bring the form to the Social Worker or the Transplant Nurse Coordinator for assistance with completion.

Health Care Proxy/ Living Will/ Power of Attorney/ Guardianship:

The Social Worker can assist you, or refer you for assistance, with obtaining these powers or completing associated documentation.

Job Training/ Returning to Work:

Many kidney transplant patients work right up to transplant, and return to work after several weeks. Some others may have been out of the workforce for months or even years, but now or in the future, may be capable of and be expected to return to work (if the disability is relieved by transplant). SSDI has incentives available to encourage your return to part-time or full-time work. The Massachusetts Rehabilitation Commission is available to help prepare patients for this transition. Speak with the social worker for more information.

Medic-Alert Jewelry:

EVERY PATIENT WITH A KIDNEY TRANSPLANT SHOULD WEAR A MEDIC-ALERT BRACELET.

Please ask the Social Worker or Transplant Nurse Coordinator for more information.

Medicare:

If you are not on Medicare prior to your transplant, it is strongly recommended that you apply within twelve months after transplant, retroactive to the month of transplant. Extended coverage for immunosuppressive medications may depend upon Medicare being in place. Please talk with the Social Worker or Transplant Finance Coordinator about why this is important in your situation, and how to apply.

Medicare also provides prescription drug coverage (Medicare Part D) for people who need assistance paying for generic and brand name prescription medication. Like Medicare Part B, Medicare Part D has a monthly premium. There are many different plans to choose from, with

different benefits and costs. Not every plan pays for every medication, so when you are choosing a plan, be sure that it covers the medicines you need. If you need help choosing a plan, call Medicare at 1-800-MEDICARE, or visit www.medicare.gov. The transplant financial coordinator can also be helpful.

Ask your Transplant Social Worker, Finance Coordinator or call 1-800-Medicare if you qualify for the low income subsidy for Medicare Part D. If you qualify, you must apply in order to avoid the monthly premium and “donut hole” financial liability.

If you already have prescription drug coverage that is at least as good as what Medicare offers, you may be advised not to get Medicare D at this time. However, if you do not have prescription drug coverage that is at least as good as what Medicare offers and you still decide not to get Medicare D now but you do get it in the future, a 1% surcharge will be added to the premium you pay for every month that you delayed getting Medicare Part D.

Medication Coverage:

The Transplant Financial Coordinator and Social Worker can help you understand the complexities of prescription coverage, as they apply to your situation, and help you to anticipate your immediate and long-range medication coverage needs. Proper coverage is critical for your health and the health of your kidney transplant. It is expected that you and/or your support person become well versed in your insurance and drug coverage options and related benefits, and that you will actively anticipate and plan for changes and future needs. We anticipate that you will keep us notified of any expected or actual changes in coverage.

Section 1: Introduction to Kidney Transplant

1.4 Other Useful Information

Brigham and Women's Hospital:

www.brighamandwomens.org/Departments_and_Services/surgery/services/transplantsurgery/Default.aspx

- Transplant Surgery Office: 617.732.6866
- Renal Transplant Clinic: 617.732.6383
- Medication refills: 617.732.4894
- Transplant Finance Coordinator 617.525.7415
- Transplant Social Workers: Barbara Levine-617.732.7882, Annette Pimenta-617.732.6480
- Patient and Family Relations: 617.732.6636
- Care Coordination Dept: 617.732.6469
- Patient and Family Relations: 617.732.6636
- Spiritual Care: 617.732.7480

Masshealth Customer Service: 800.841.2900. www.mass.gov

Medicare: www.medicare.gov

Quitworks: Tobacco Treatment: 800.879.8983

Social Security Administration: 800.772.1213. www.ssa.gov

Transportation:

- Senior Shuttle: 617.635.3000. www.cityofboston.gov/elderly/transportation
- The Ride: 800.533.6282. www.mbta.com

Brigham and Women's Information

Pay Phones: Located on each inpatient floor near the elevator, in the public corridor of each floor and in the main lobby at 75 Francis Street. Cell phones are not permitted on inpatient floors.

ATM: Behind the stairs in the main lobby/atrium at 75 Francis Street and in the lobby of 45 Francis Street

Gift and Flower Shop: Second floor, at the top of the escalators that run from the 75 Francis Street lobby up to the bridge to the Shapiro Building. 617.732.7445

Interfaith Chapel: Next to the first floor Tower elevator bank in the 75 Francis Street lobby

Outpatient pharmacy: Second floor of the main corridor (The "Pike"), Exit 6. 617.732.6922

Section 2: Before Your Kidney Transplant

- 2.1 What Happens When Your Kidneys Fail?
- 2.2 Being Assessed For a Kidney Transplant
- 2.3 Tissue Typing and 'Matching'
- 2.4 Types of Kidney Transplants
- 2.5 The Kidney Transplant Waitlist

Section 2: Before Your Kidney Transplant

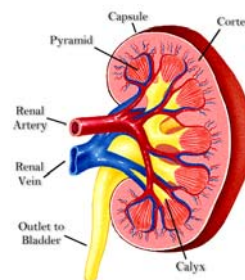
2.1 What Happens When Your Kidneys Fail?

The Kidney:

The kidneys are two bean shaped organs located in the back under the lower part of your rib cage. Their main function is to excrete excess fluid and waste material from your body.

Chronic Kidney Disease:

When your kidneys lose their ability to work properly over time, you are considered to have chronic kidney disease. There are stages (stages 1-5) of kidney disease based on how much kidney damage you have; Stage 5 is the most advanced, necessitating dialysis treatment or transplant.



Kidney Failure: (also called End Stage Renal Disease or ESRD)

Kidney failure is when your kidney loses the ability to eliminate fluid and waste and these build up in your body. Kidney disease usually develops slowly over time. Many people do not realize they have kidney problems until they have lost more than 75% of their normal kidney function.

Some Symptoms of Kidney Disease: (not everyone has these)

- High blood pressure
- Unexplained weight loss
- Nausea or vomiting
- Fatigue
- Headaches that seem unrelated to any other cause
- Decreased urine output
- Decreased mental sharpness
- Muscle twitches and cramps
- Yellowish-brown color to the skin
- Persistent itching
- Sleep disorders

Most common causes/risk factors for developing kidney failure:

- Diabetes
- High blood pressure
- Obstruction: large prostate, kidney stones, tumors
- Glomerulonephritis
- Polycystic kidney disease
- Long term use of medications such as ibuprofen (Advil, Motrin, Aleve)

Diabetes and high blood pressure can cause or make kidney disease worse. Therefore, it is important that your diabetes and blood pressure are well controlled.

Screening for Kidney Disease:

If your doctor suspects that you may have kidney failure you may need one of the following:

- Blood tests assessing for abnormalities such as increases in creatinine and urea
- Urine tests assessing for protein or blood in your urine
- Imaging studies such as ultrasounds, computerized tomography (CT) scan, or magnetic resonance imaging (MRI)
- Kidney biopsy: a small sample of kidney tissue is sent to the lab for analysis

Effects of Kidney Disease:

Chronic kidney disease can affect other parts of your body, including:

- Increased fluid: this may lead to swelling in your legs
- Rise in potassium levels in your blood: this could impair your heart's ability to function and may be life-threatening
- Weak bones that fracture easily
- Anemia:
- Development of stomach ulcers
- Changes in skin color
- Damage to your central nervous system
- Insomnia

Treatment Options:

If your kidneys fail, you have the following treatment options:

1. **Dialysis** – This is a technique of removing fluid and waste products from your body with a dialysis machine. This machine acts as an artificial kidney. This method of using a dialysis machine is called hemodialysis and requires that your blood be slowly passed over a filter and then returned to your body

Peritoneal Dialysis - is a different dialysis option, when a small tube is placed in your abdomen. Fluid is put into your abdomen which then absorbs wastes and extra fluid from your body before being drained out of the tube again. This needs to be done several times a day and is done by the patients themselves at their home or work.

2. **Kidney Transplant** – When a new kidney is placed into your body, to replace those functions of your own kidneys and give you a healthier life off of dialysis.

Section 2: Before Your Kidney Transplant

2.2 Being Assessed For a Kidney Transplant

Getting a Kidney Transplant – What is involved?

The first step in getting a kidney transplant is determining if you are healthy enough. A kidney transplant is a major operation and if you have serious medical problems, it may be too risky to undergo. After transplant you need to take a lot of medications to keep your kidney healthy and many of these medicines have side effects that can be dangerous if certain medical conditions exist.

There are four parts to the evaluation process

1. Visiting the transplant center

- The Transplant Center will work with your doctor, nurse or social worker to arrange this visit. You can also call the transplant center on your own and ask to be evaluated.
- Your medical records will need to be sent to the transplant center to:
 - Understand how transplant may affect any other medical conditions you currently have
 - Review your diet and weight history
 - Understand how to tailor your transplant center visit to your health history
- In addition, our financial coordinator will review your health insurance details to avoid problems getting medications after transplant.

2. Having your physical health screened

- At the transplant visit, you will meet your new transplant nurse coordinator and thoroughly discuss your current medical conditions.
- You will meet the transplant surgeon and transplant nephrologists separately for a history and physical examination.
- You will also be seen by the transplant social worker
- These initial appointments can take several hours so please expect to be at the transplant center for at least half a day.
- You will have multiple tubes of blood drawn for tissue typing (determining your blood type) and other laboratory tests
- The Transplant Team will often ask for tests that evaluate:
 - your heart, bladder, and blood vessels
 - your risk for cancers
 - your risk for infections

NOTE: We will try to reduce the number of trips to the hospital needed to complete these studies, but a complete evaluation may require additional visits.

It is important that you continue to see your primary care physician for your routine health care issues throughout this process.

3. Having your mental health evaluated

- The social worker will evaluate your mental health and social supports
- They may recommend that you see a psychologist or psychiatrist to assess:
 - Any use of alcohol or drugs
 - Whether you have any emotional stressors that may interfere with your health
 - Your ability to withstand the emotional stress that can develop due to having a kidney transplant.
- **Having a history of depression or mental illness does not exclude you from having a transplant.**

4. Transplant Team Decision-Making:

- Each transplant candidate is reviewed by the entire transplant team before final approval is given.
- You will not be approved for transplant until all requested tests are complete and all recommendations have been followed. Once it is determined that you are a good candidate for kidney transplantation, the transplant team will work with you to find the best kind of transplant for you.

If you have any medical tests or investigations while you are being evaluated for transplant, please ask your physicians to let the Transplant Office know the results. Fax 617.582.6167, to the attention of your nurse.

Section 2: Before Your Kidney Transplant

2.3 Tissue Typing and 'Matching'

As part of your workup for kidney transplant, blood tests will be sent to the Tissue Typing Lab for a number of tests, including:

1. Typing your blood group

It is important that you and your kidney donor have compatible (not necessarily identical) blood types (the process of determining this compatibility can also be called "matching"). We will tell if you are compatible with your potential donor.

2. Determining your Human Leukocyte Antigen (HLA) type

Your HLA type is a set of up to six unique genetic markers found on your blood cells and is part of what makes you, "you". These proteins are present on each individual's cell and allow the immune system to recognize 'self' from 'foreign'. Your potential donor(s) will also have their HLA type determined. The closer the HLA type is between a donor and recipient, the better the "match" of the kidney. Better matched kidneys MAY have better outcomes.

Now that we have excellent drugs to suppress the immune system after transplant, the amount of matching is still important, BUT even if a kidney is not matched at all, it will still likely last a long time.

3. Testing your blood for SENSITIZATION or PRA

Sensitization means that you have proteins (called antibodies) circulating in your blood that can potentially react with a donor kidney and cause severe damage. *Antibodies are a normal part of your immune system.* People can become sensitized to potential donor kidneys if they have had a prior kidney transplant, multiple blood transfusions, or have been pregnant. Even if you have had none of these, you may still be sensitized.

Panel Reactive Antibody (PRA) is an immunological laboratory test that is routine for people awaiting organ transplantation. The PRA score is expressed as a percentage between 0% and 99%. The lower the number, the fewer the antibodies are in your blood. Individuals with a high PRA are often term 'sensitized'. While you are on the transplant waitlist, a blood sample will be sent every month to the tissue typing lab so we can monitor your PRA, as it often changes over time.

NOTE: IT IS IMPORTANT THAT YOU HAVE THIS BLOOD SAMPLE DRAWN EVERY MONTH.

4. Crossmatching

This monthly sample will also be stored in the Tissue Typing Lab and if a possible kidney becomes available for you, we use the most recent sample to ensure that you do not have any dangerous antibodies to that *PARTICULAR* kidney. This test is called a CROSSMATCH.

If we do not have a recent sample in the lab for you, you may miss out on a kidney!

Section 2: Before Your Kidney Transplant

2.4 Types of Kidney Transplants

The next part of the process is finding the right kidney for you. There are two main types of kidney transplants:

1. Living donor transplants

- This is a kidney transplant in which a kidney is given to you by another living person.
- This living person may fit into one of two groups
 - Blood relative (living related donor transplant): such as a parent, sister, brother or child
 - Non-blood relative (living unrelated donor transplant): such as a husband/wife, stepchild, or adopted parent or child or friend
- Living donation is preferred because it offers the best opportunity for the best quality kidney and the shortest waiting time.
- The living donor is thoroughly evaluated to ensure that the removal of a kidney will not harm his or her health. This process is done by a different doctor than the one who evaluates you.
- There is no guarantee that someone who wants to be able to donate a kidney will be able to, as there may be health, emotional or social issues that can preclude them from donating.

Sometimes a person may want to donate a kidney to you but cannot because their blood type is not compatible with yours. There are options in this case:

- Join the National Kidney Registry (NKR) and potentially become part of a paired kidney exchange: when a living kidney donor/recipient pair is incompatible, they can exchange kidneys with another donor/recipient pair in a similar situation.

Your transplant team will tell you if being part of a kidney exchange is a good choice for you.

2. Deceased donor transplants

A. Standard deceased donor transplants

- If receiving a kidney from a living donor is not an option, your name will be placed on the national wait list for a deceased donor kidney
- This kind of kidney is taken from a person who has suffered brain death. The family of this donor has made the decision to offer their kidney for transplant to help others.
- Kidneys from deceased donors are a precious national resource, and a nationwide program is designed to allow equal access to all patients who need a kidney transplant. This national system balances the needs of patients who have been waiting for a long time on the waitlist, with the goal of transplanting well-matched kidneys.
- In general, the wait time for a deceased donor kidney is longer than for a living donor kidney, and there is no guarantee that you will receive a deceased donor kidney.

B. Expanded criteria deceased donor transplants

- Because the supply of deceased donor kidneys is not enough for all the patients waiting for kidneys, our transplant program is willing to accept SOME kidneys from deceased donors that may be slightly less than perfect; these are called “expanded criteria donors” (ECD). An ECD donor has one of the following criteria:
 - Age over 60
 - Age over 50, along with one of the following:
 - History of high blood pressure
 - Stroke as cause of death
 - Mild kidney damage at the time of death (Cr 1.5-2.0 mg/dL)
- Many of these kidneys function very well for several years however there is an increased risk of early and late kidney loss.

Section 2: Before Your Kidney Transplant

2.5 The Kidney Transplant Waitlist

The Waitlist is a list of potential transplant recipients generated by The United Network for Organ Sharing (UNOS). UNOS maintains a centralized network linking all transplant centers. Their organ placement specialists operate the network twenty-four hours per day, seven days a week.

All patients accepted by the Brigham & Women's Transplant Program are registered on the UNOS Waitlist. The day you are activated/listed is the day you begin accumulating time. You will receive a letter stating that you are listed and indicating your waitlist status.

Status 1, means you are active, gaining time and eligible to receive a kidney.

Status 7, means you are active, gaining time but not eligible to receive a kidney. Examples of why you might be status 7 are:

- a. You have a current medical problem which needs sorting out.
- b. You are working on getting the proper insurance to cover transplantation.

Don't worry; we will work with you on these issues to get you back to Status 1 as soon as possible.

Once you are Status 1 it is very important for us to know how to get in touch with you. We need to have all your phone numbers: home, work & cell. Please keep your cell phone charged and on at all times. Once you are Status 1 you could be called at any time, day or night.

IF YOUR CONTACT INFORMATION CHANGES PLEASE LET US KNOW AS SOON AS POSSIBLE at 617-732-6866.

The amount of time that you wait for a kidney depends on a lot of different factors including your blood type and how "sensitized" you are to potential kidney donors. (See Section 2.3 Tissue Typing and Matching)

You can still look for live donors when you are on the transplant waitlist. The waitlist times for kidney transplant are, on average, between 2 and 6 years.

The Expanded Criteria Donor (ECD) Waitlist

Both ECD and Standard Deceased Donor Kidney transplants are available at Brigham & Women's Hospital. ECD transplant is under the direction of UNOS and helps certain types of recipients receive transplants in a more timely fashion.

The ECD waitlist is a list within the larger UNOS Waitlist. The criteria for these donor kidneys are slightly less stringent. Candidates who agree to receive an ECD kidney are **also** eligible to receive a standard donor kidney.

Appropriate candidates for the ECD list are usually older or have medical problems, which warrant some urgency to transplant. Registration on the ECD list would occur only after your nephrologists and surgeon have thoroughly discussed the pros and cons with you.

Section 3: At the Time of Your Transplant

- 3.1 The Transplant Procedure
- 3.2 Discharge Instructions
- 3.3 Discharge Checklist
- 3.4 Hospital Re-Admission
- 3.5 Writing To The Donor Family

Please also use the following brochures available from the Transplant Program Office or the Bretholtz Center for Patients and Families (behind the security desk at 75 Francis St.):

New Patient Information Handbook: a transplant-specific booklet regarding general information about Brigham and Women's Hospital, including directions, parking, accommodations, etc.

Patient and Family Resources: a quick reference to Brigham and Women's Hospital Services

The Bretholtz Center for Patients and Families:

- Patient and Family Relations
- The Health Education Library
- The Family Liaison Service

A Guide to Your Hospital Stay:

- Pre-admission center
- Pre-surgery preparation
- A Typical Day in Hospital
- Who you will meet in Hospital
- Patient and Visitor Services
- Patient's Rights and Responsibilities

Section 3: At the Time of Your Transplant

3.1 The Transplant Procedure

The surgical procedure for kidney transplantation has been perfected over many years. Patients often have many questions about the transplant operation. For your information and reference, here are some frequently asked questions:

Where inside my body will the new transplanted kidney be placed?

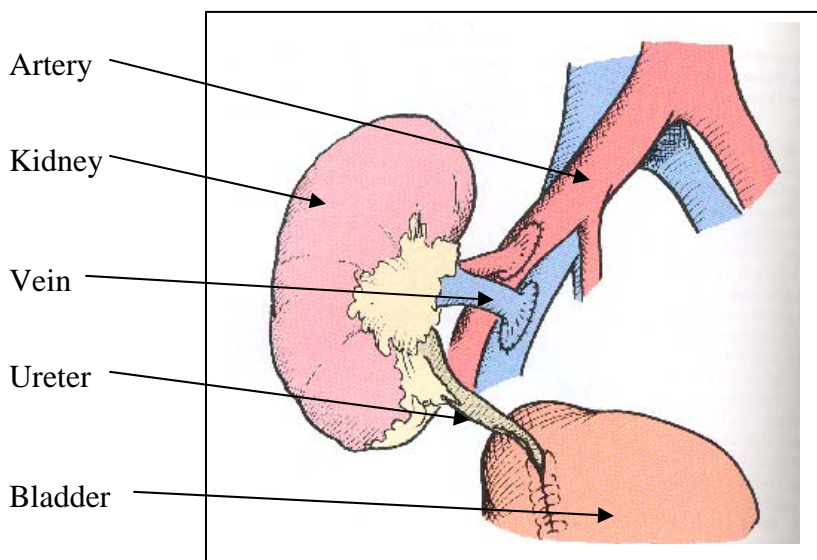
The kidney will be placed on the right or lower left side of your abdomen.

Technical aspects

The artery and vein of the transplanted kidney will be connected to arteries and veins in your pelvis. The ureter (the vessel that collects the urine from the kidney) will be connected to the bladder.

How long will the surgery take?

The surgery generally takes between 2 and 4 hours.



Kidney transplantation to the right lower abdomen. Artery and Vein of the kidney are connected to the artery and vein of the pelvis (Iliac artery and vein). The Ureter is connected to the bladder. The muscle layer of the bladder is closed on top of this connection to prevent backflow into the kidney.

Will I need to have my own kidneys removed?

In general, this is not necessary. However, there might be situations in which you will benefit from the removal of your kidneys. We will discuss this with you on an individual basis.

Where will I be after the surgery?

Following the completion of the surgery you will be taken to a special floor with care providers experienced in kidney transplantation. In some situations, or when a patient has additional diseases, he/she may benefit from a short-term stay on an intensive care unit (ICU). We are happy to discuss this with you in detail.

Do complications occur that are related to the surgery?

Unfortunately, complications can occur during or after surgery. They are rare, and we can assure you that we always do our very best to avoid them.

Potential complications:

Thrombosis, or clot, of the kidney artery and vein (occurs only about 2-5% of the time):

This is a rare, however severe complication. Thrombosis can stop blood flowing into the kidney. We follow such an event very closely. If your kidney does not produce urine immediately we will perform an ultrasound of the kidney every day to make sure that there are no clots that have formed.

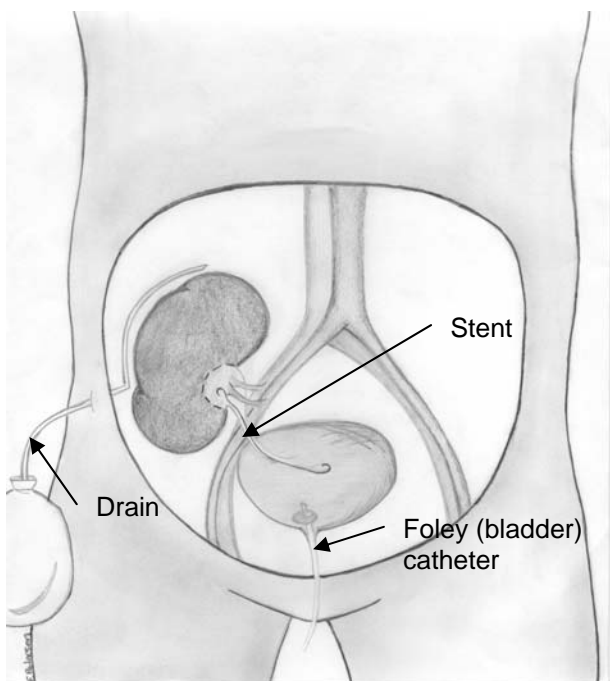
Leakage from the connection of the ureter to the bladder (occurs only about 4-6 % of the time):

We try to avoid this complication by stenting the ureter. The stent will remain for 6 weeks after the transplantation to assure that the connection of the ureter to the bladder is well healed. In addition, you will have a foley catheter in your bladder after the surgery: This will make sure that your bladder is decompressed and that the connection between the ureter and the bladder will heal well. Recent scientific reports have shown that these measurements will reduce the risk for a leak.

Any complication that can happen after any type of surgery can, of course, also happen after a kidney transplant. They are rare and include:

- Bleeding from the wound side.
- Local (e.g. skin) and systemic (e.g. urine or lung) infections.
- Thrombosis located in the area of your lower extremities. The risk of this complication can be greatly reduced if you get up and walk around as soon as possible after surgery.

Stents, Drains, Staples: When will they be removed?



Drains around your kidney or below your skin will collect fluid and will be removed once they drain less than 30 cc/d (approx. after 1 week). The stent protecting the connection of the ureter into the bladder will be removed after 6 weeks during a cystoscopy under local anesthesia

Stent:

A stent is a tube that is placed from the kidney through the ureter and into the bladder to protect the connection between your ureter and the bladder.

Normally, this stent will be removed 6 weeks after the surgery during a cystoscopy under local anesthesia. The procedure is similar to having a foley catheter placed. You WILL be able to drive after this procedure.

Drains:

You will have 1 or 2 drains collecting fluid around your transplanted kidney and below the skin.

The drains will be removed after about one week (or once they collect less than 30 cc in a 24 time period). If we take them out too soon, fluid collections can form around the kidney. To avoid this, in some patients, we keep the drains in for a longer period (2-3 weeks).

Staples:

Usually we close the skin with staples. Those will be removed after 14 days.

How long will I need to stay in the hospital?

Usually you will be in the hospital for 5 – 7 days.

How long is the recovery period?

Most likely you will be back to your normal exercise level in about 4 weeks. We recommend that you do not operate a vehicle for 4 weeks immediately after the transplant.

Post-Operative Visit:

You will be seen twice a week after transplant. These appointments will be scheduled for you at the time of your discharge.

Section 3: At the Time of Your Transplant

3.2 Discharge Instructions

You will receive detailed discharge instructions *specific to you*, from your nurse and physicians before leaving the hospital.

We have also included here in this section some general post-operative recommendations:

Diet

It is important to make sure you drink enough fluids after you leave the hospital. 2 – 2.5 liters (about 64 oz or 8-10 cups) per day is appropriate. It is normal to have a slightly decreased appetite after major surgery. Take it easy and eat what feels right. If your kidney function is normal, you will have no dietary restrictions except for grapefruit or anything containing grapefruit (grapefruit can interact with transplant medications).

Monitoring your kidney

It is important to check your blood pressure, and follow your fluid intake, and your urine output, and your weight. For more details on monitoring your transplanted kidney, please see Section 7.

Activities

Patients and families often have questions about the level of activity that is safe for the patient after they leave the hospital. Most people feel more tired than they expect to when they get home. Often, whether or not you are up to a particular activity will depend upon whether or not you are back to a regular well balanced diet and a good sleep pattern.

Once you are at home, start out by doing just those activities you know you can do (those you already did while in the hospital). Think about adding one new activity at a time and make sure you are well rested when you begin. You should plan on taking pain medicine, if needed, half an hour before trying a new activity. Avoid doing exercises that strain your abdominal incision (e.g. crunches, heavy lifting) until checking with your doctors.

Start by spending 10-15 minutes on the new activity to see how you feel. Begin slowly and pace yourself. If you feel tired, you can slow down or stop and plan to try a little later. Doing a little at a time will help you to build your strength and endurance. Frequent rest periods will help you to stay active during recovery from any illness. If you feel short of breath or have chest pain, you should check with your doctor immediately.

The following table includes common daily activities listed by how much work or energy they require. Activities at the top take the least energy. These recommendations are based on our general collective experience and common sense. We encourage you to discuss each item below with your nurses and doctors to get the most appropriate information specific for you.

Activity	When to Resume....
Taking a tub bath	If you have an incision on your abdomen it is best not to bathe for two weeks to prevent infection and allow for complete healing
Taking a shower	You can resume showering immediately, but allow the water to run over your incision. Avoid having the water hit it directly. Dry the incision completely by gently patting instead of rubbing.
Lifting	With an abdominal incision, avoid lifting more than 15 lb (about the weight of a bag of groceries) for 6 weeks to allow your inner tissues and muscles time to regain their usual strength
Walking/Exercising	You can resume walking immediately for <u>short</u> distances, but don't allow yourself to become overly tired or dehydrated. Swimming and moderate exercise is generally fine after 4-6 weeks.
Climbing stairs	When your strength and balance have returned
Sexual activity	When you feel comfortable or as instructed by your doctor
Driving	Not until you have stopped taking pain medication.
Back to work	After discussion with your doctors
Travel	After discussion with your doctors

If you experience any of the following symptoms when you go home, please call the transplant clinic nurses (DAYTIME) or the renal transplant fellow on call (evenings and weekends ONLY in case of emergency):

- Temperature >100.5F
- Large decrease in your urine output (for example < 4 cups per day)
- Signs of infection (redness, swelling, increased pain, pus)
- Nausea and vomiting and unable to keep medicines down
- Sudden or easy bruising
- Increased pain despite pain medications
- Blood in urine
- Rapid weight loss or gain

GO IMMEDIATELY TO THE EMERGENCY ROOM IF YOU HAVE:

- Black, tarry stools or blood in stools
- Chest pain, shortness of breath, rapid heart beat
- Leg or calf swelling, tenderness or redness
- Sudden weakness or numbness on one side of the body or the face.
- Sudden change in vision
- Difficulty talking
- Sudden severe headache

Section 3: At the Time of Your Transplant

3.3 Discharge Checklist

Please use this list to help you think about the things you will need before you leave the hospital. We will do everything we can to help you prepare for your discharge, but it is also your responsibility to make sure you have all your questions answered before you leave.

Before you leave the hospital, you will be seen by:

- Your attending surgeon and nephrologist
- Renal Pharmacist
- Transplant Social Worker
- Physical therapy
- Transplant Clinic Nurse

You should feel comfortable with:

- All of your medications
- Wound care and dressing changes if necessary
- Your Foley Catheter if necessary
- Your blood sugar monitor if necessary
- Measuring your own blood pressure
- Measuring your fluid intake and urine output

At the time of discharge please confirm that:

- You have a ride home and they know what time to come to the hospital
- You have received your CarePlus Package
- You have your first follow-up appointment booked and a way to get there
- You have the Clinic and Transplant Nurses' phone numbers
- Your address and phone number are correct on your discharge papers
- Your doctor has signed your labs slips at the front of this book

Section 3: At the Time of Your Transplant

3.4 Hospital Re-Admission

You may have to come back to the Emergency Room or into the hospital if you get sick after your transplant, or if you need a kidney biopsy.

No matter what reason you are being admitted (either related to your transplant or for a different problem), **please make sure you always bring/know the following:**

- This Transplant Handbook
- Medication List (up to date)
- Actual medication bottles if you do not have a medication list
- List of your physician's names and phone numbers/contact information
- Toiletries and an overnight bag
- Name and contact information of the person we should call in case of an emergency
- Health care proxy information and/or living will (please see the Advanced Care Directive Booklet in the front pocket of this handbook).

Section 3: At the Time of Your Transplant

3.5 Writing to the Donor Family

Writing to your donor family is a personal decision

Transplant recipients of deceased donor kidneys may choose to write to their donor family to express gratitude for the gift they received.

Many donor families have said that a card or personal note from a recipient of their loved one's kidney offers comfort and consolation.

What you might write about

- Talk about yourself, your job, hobbies, interests and family. We suggest that you do not include religious comments in your letter
- Your transplant experience. How long you waited, what the wait was like for you and your family
- Explain how the transplant has improved your health and changed your life
- Events in your life since the transplant: Did you celebrate another birthday? Did your son or daughter marry? Did you become a parent or grandparent? A new job?

What you MUST NOT write about

The New England Organ Bank supports written correspondence between recipient and donor family, but **all correspondence is anonymous and identities are kept confidential.**

Please make ***no reference*** to:

- Your name (you may sign your first name if you choose)
- Your address, city, or telephone number
- The name or location of your transplant center or physician

Mail your letter to the New England Organ Bank

- When closing your card or letter, you may sign your first name if you choose.
- Place your card or letter in an *unsealed* envelope
- Include in the envelope, on a separate piece of paper, your full name, and the date of the transplant.
- Place these items in another envelope and mail to **the New England Organ Bank, 300 Washington Street, Newton, MA 02458, Attn: Donor Family Services**

The New England Organ Bank Donor Family Services Representative will review your card or letter to ensure confidentiality and then notify your donor family that correspondence has arrived for them from you. If they are ready to receive your correspondence, the Donor Family Services Representative will forward your letter. You may or may not receive a response from your donor family. Remember, the donor family may still be coping with the loss of their loved one and individuals manage grief in different ways. For information about the New England Organ Bank, please visit their website: www.neob.org.