Brigham and Women's Hospital
Founding Member, Mass General Brigham

HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

Brigham and Women's Kidney Transplant Program

Pre-Transplant Handbook

Mass General Brigham

DAYTIME: Monday – Friday, 8:00a – 4:30p
Call the Transplant Surgery office at 617.732.6866, option 2

For non-urgent questions and appointment changes, Please use Patient Gateway/MyChart.

- **Allow 3 days for routine messages**
- **Not staffed outside of normal office hours**
- **Handled by the care team, not just the doctor**
- **Not for new symptoms or possible emergencies**

For emergencies or questions after 4:30 pm, weekends, or holidays:
call the BWH Operator: 617.732.6660
Ask for the "Renal Transplant Surgery Resident On-Call"

Transplant Surgeons

Tel: 617.732.6866, option 4
Fax: 617.525.0431
Dr. Stefan G. Tullius, Program/Surgical Director
Dr. Sayeed Malek, Clinical Director
Dr. Richard Teo

Pre-Transplant Nurse Coordinators

Tel: 617.732.6866, option 2
Fax: 617.525.0431
Kevin Calderone, RN
Nancy Minghella, RN
Christine Possi, RN

Pre-Transplant Administrative Coordinators

Tel: 617.732.8248
Fax: 617.525.0431
Cheydalyn Guzman
Sydney Vo

Living Donor Coordinators

Fax: 617.394.3217
Kristen Pelletier, RN
Tel: 617.732.8683
Annemarie Dunn-Morgan, RN
Tel: 617.278.0030

Living Donor Administrative Coordinator

Tel: 617.732.5644
Fax: 617.394.3217
Jayla Greene

Transplant Nephrologists

Tel: 617.732.6383
Fax: 617.394.3218
Dr Jamil Azzi, Interim Medical Director
Dr. John Choi
Dr. Rania El Fekih
Dr. Martina McGrath
Dr. Edgar Milford
Dr. Nader Najafian
Dr. Brittany Schreiber
Dr. Melissa Yeung

Post-Transplant Nurse Coordinators

Tel: 617.732.6123, option 3
Fax: 617.394.3218
Julie Bettencourt, RN
Sybil Bleus, RN
Elizabeth Dopler, RN
Christine Matthews, RN
Marylou McSolla, RN
Sheila Patterson, RN

Transplant Pharmacist

Tel: 617.732.7658
Fax: 617.732.7507
Kaitlyn Lei, RPH, PharmD, BCTXP

Transplant Financial Coordinator

Tel: 617.525.3155
Fax: 617.525-0511
Linda T. Jones, MBA

Transplant Nutrition

Tel: 617.732.6054
Fax: 617.732.7024
Inpt: Emily Trussler, RD
Outpt: Dieticians of the Nutrition & Wellness Service

Transplant Physician Assistants

Pre-Transplant*:*
Tel: 617.525.8239
Trisha Auduong, PA-C
Post-Transplant:
Tel: 617.732.5951
Tel: 617.732.6383
Emily Burkart, PA-C
Kimberly Campbell, PA-C
Jillian Hamlin, PA-C
Sara Hammer, PA-C
Helen Le, PA-C
Jillian Lynch, PA-C
Jennifer Lynett, PA-C
Kaitlyn McGowan, PA-C
Kristen Paolucci, PA-C
Katie Ryder, PA-C

Transplant Social Workers

Fax: 617.525.0431
Ashley Abreu, LICSW
Tel: 617.732.7882
Annette Pimenta, LICSW
Tel: 617.732.6480

TABLE OF CONTENTS

HOW TO USE THIS BOOK:

This handbook helps you through each stage of kidney transplantation. Please take your time to read through the booklet. We recommend starting at the sections that apply to where you are *now*. There is a lot of information, but you will feel familiar to kidney transplant with time. Until then, you can use this booklet as a reference.

**** Please remember to bring this book with you every time you meet with your transplant care team.***

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 Brigham and Women's Hospital Kidney Transplant Program. We encourage you and your family to read this book **completely and often** – both before and after your transplant. This booklet, and the other resources provided, will help you to have a better understanding of the entire transplant process.

Please visit our website for additional information: www.brighamandwomens.org/renaltransplant. Our team of transplant physicians, transplant pharmacists, physician assistants, transplant nurses, and transplant social workers are happy to answer questions you may have about the transplant process.

Topics in this booklet include:

- Your evaluation as a transplant candidate
- The types of kidney transplants available
- Transplant surgery and what you can expect
- Anti-rejection medications after transplant
- Follow up visits after transplant
- Who to contact
- Returning to work and other activities
- Healthy eating after transplant

A kidney transplant is a "gift of life," and we hope this booklet will guide you throughout the process.

Sincerely,

The Kidney Transplant Team at
Brigham and Women's Hospital

Kidney Disease and Transplant Information Web Resources:

- **New England Donor Services (NEDS):**

  www.neds.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.

- **American Association of Kidney Patients**:

  www.aakp.org 800-749-2257– Provides education, advocacy, and builds communication with 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://donatelife.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**:

  www.kidney.org – 800-542-4001. Leading health organization dedicated to fighting kidney disease.

www.kidneyhealth.org : New England branch of the National Kidney Foundation

- **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**:

  www.ktda.org – 781-641-4000. 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 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.

Your Transplant Social Worker and Transplant Financial Coordinator are helpful by providing information, referrals, or counseling. Please contact them for further information or assistance in any of these areas. They are on your transplant team and available to you before, at the time of, and after your transplant.

Your transplant Social Worker can help with:

<u>Adjusting to your new medications</u>:

You will start several new medications after you receive your kidney transplant. It is very important to take these medications as instructed by your physician.

As a transplant patient you ***need*** to take care of your health. We expect you to take responsibility for teaching yourself about your kidney and how to stay healthy. Research tells us that by not taking your medications as told will result in Rejection.

Please talk to your transplant caregivers if you are facing barriers to good compliance.

<u>Mental Health Services:</u>

Patients may find the transplant process very challenging, both physically and mentally. 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 emotional help and support is available from your transplant:

- Medical providers
- Social Worker
- Renal Transplant Psychiatrist
- Referral to a mental health clinician in your area.

We encourage you to attend our monthly support group which provides support and education about transplant. Several of our past support groups and educational offerings can be found on our website under patient support and education.

*Please call your social worker or speak to the transplant team ***as soon*** **as possible** if problems start to occur. *

<u>Post-Transplant Support:</u>

Having strong support from family, friends and/or members of your community is an essential part of a successful outcome after transplant.

- Your social worker will provide education on the responsibilities of your support team.
- You will be given a support team worksheet for you and your primary support to fill out and return.
- Your social worker can assist you with developing and strengthening your support team.

Your transplant Financial Coordinator can help with:

Insurance and Coordination of Benefits:

If there are any changes AT ALL in your insurance, it is important that you contact the transplant financial coordinator ***immediately***. Lack of insurance coverage carries the risk of inability to pay for your, medications which is crucial to the success of transplant.

The transplant office cannot supply medications for you – this needs to be your responsibility. The financial coordinator 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 all insurers informed when you add or lose coverage.

* This ensures billing occurs in the proper sequence (primary vs. secondary coverage).

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. Some have waiting periods and time limits. A social worker can explain criteria and how to apply for the right program(s) for you.

Living 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:
Phone: 617-525-7415;
fax: 617-525-0431.

Family Medical Leave Act (FMLA):

Provides a designated amount of unpaid leave and job security for most employees who are ill.

Depending on which state you live in, you may also have eligibility for paid leave through State Disability Insurance.

Family members/caregivers also may qualify.

Social workers can help answer questions about this resource. Forms should be brought to your medical provider for completion.

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

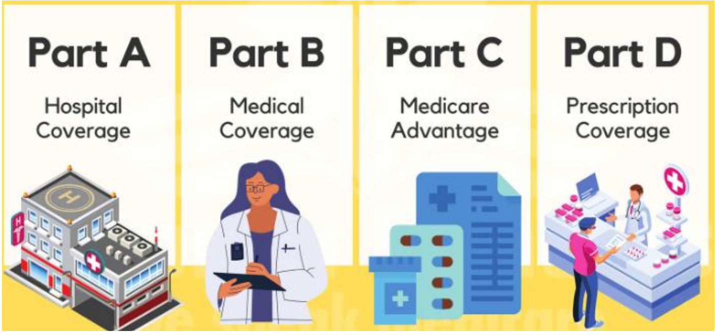
The Social Worker can assist you, or refer you for assistance, with obtaining these powers or completing associated documentation.

Job Training/ Returning to Work:

- Many patients can work up until time of transplant and return to work after several weeks.
- 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 further information.

Medicare:



If you are not on Medicare prior to your transplant, it is recommended that you talk with either the Social Worker or Transplant Financial Coordinator about your situation, and how to apply.

- Medicare 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 different plans to choose from with different benefits and costs.
- Not every plan pays for every medication. When you are choosing, be sure 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 Financial Coordinator or call 1-800-Medicare if you qualify for the low-income subsidy for Medicare Part D. You must apply to avoid the monthly premium and “donut hole” financial liability.

If you already have prescription drug coverage that is as good as what Medicare offers or better, you may be told not to get Medicare D at this time.

However:
if you do not have prescription coverage that is as good as Medicare and you 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 can help you understand the complexities of prescription coverage, as they apply to your situation, and help you predict your near 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 understands your insurance and drug coverage options and related benefits, and that you will actively predict and plan for changes and future needs.
- We expect that you will keep us notified of any anticipated or actual changes in coverage.

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: 617-525-3477
- Transplant Finance Coordinator 617.525.7415
- Transplant Social Workers: Ashley Abreu-617.732.7882, Annette Pimenta-617.732.6480
- Patient and Family Relations: 617.732.6636
- Care Coordination Dept: 617.732.6469
- Spiritual Care: 617.732.7480

MassHealth Customer Service:

www.mass.gov-800.841.2900.

Medicare:

www.medicare.gov

Quitworks:

Tobacco Treatment: 800.879.8983

Social Security Administration:

www.ssa.gov- 800.772.1213.

Transportation:

- Senior Shuttle: 617.635.3000. www.cityofboston.gov/elderly/transportation
- 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’

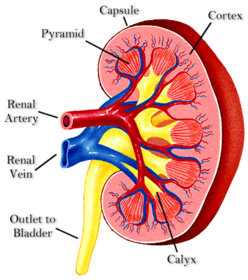
2.4 Types of Kidney Transplants

2.5 The Kidney Transplant Waitlist

2.6 Staying Healthy While Waiting

The Kidney:

- The kidney is a bean-shaped organ located in the back under the lower part of your rib cage.
- Most people are born with two.
- Healthy kidneys clean your blood and remove extra fluid, which leave the body as urine.



Chronic Kidney Disease:

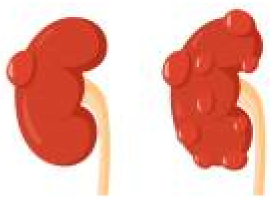
- Chronic kidney disease is a loss of kidney function over time.
- There are five stages of kidney disease.
- Many people do not realize they have kidney problems until they have lost more than 75% of their normal kidney function.

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

- Chronic kidney disease can progress to kidney failure, which is the last stage of chronic kidney disease.
- Kidney failure is life-threatening without dialysis or kidney transplant.

Most Common Causes and Risk Factors for Developing Kidney Disease:

- Diabetes
- High blood pressure
- Obstruction of the urinary tract, such as enlarge prostate, kidney stones, tumors
- Glomerulonephritis
- Polycystic kidney disease


polycystic kidney disease

- Recurrent kidney infections
- Long term use of certain medications, such as non-steroidal anti-inflammatory drugs (examples include ibuprofen, Advil, Motrin, naproxen, Aleve) or lithium

Diabetes and high blood pressure can cause or make kidney disease worse. If you have diabetes or high blood pressure, it is important for these to be well controlled.

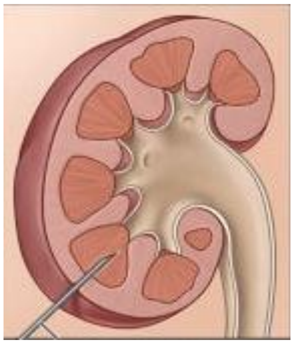
Symptoms of kidney disease may include:

- High blood pressure
- Decreased appetite
- Swelling of feet or ankles
- 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

Screening for Kidney Disease:

If your doctor suspects that you may have kidney disease, they may perform tests including:

- 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: testing a small sample of your kidney tissue



Effects of Kidney Disease:

Chronic kidney disease can affect other parts of your body. Potential complications may include:

- Fluid retention: may lead to swelling in your legs, arms, or face; high blood pressure; shortness of breath; fluid in your lungs
- Rise in potassium levels in your blood: this could impair your heart's function and may be life-threatening
- Weak bones
- Anemia
- Heart disease
- Damage to your central nervous system, which can cause difficulty concentrating, personality changes, or seizures
- Fertility and pregnancy complications

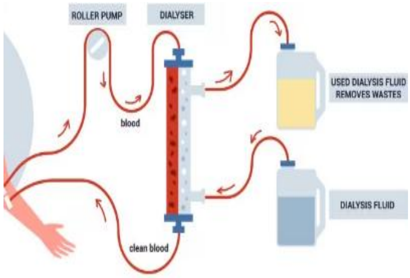
Treatment Options:

When your kidneys can no longer function well enough to keep you healthy, you have the following treatment options:

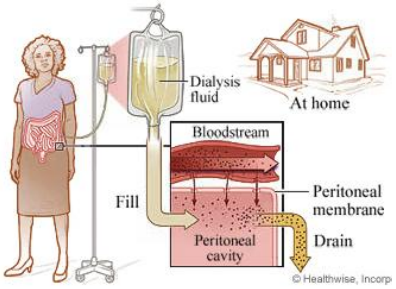
1. **Dialysis** – artificially removes waste products and extra fluid from your body when your kidneys are not functioning well enough to keep you healthy. Your nephrologist is the person to tell you when you will need to start dialysis.

   There are two types of dialysis: hemodialysis and peritoneal dialysis. The type of dialysis depends on your personal choice and medical condition. Your nephrologist can help you choose the best option for you.

   - **Hemodialysis:**
     - A machine acts as an artificial kidney to clean your blood, usually done three times per week for about 4 hours at a time.
     - Hemodialysis can be done in a hospital, in a dialysis center, or at home, depending on your medical condition.



   - **Peritoneal Dialysis**:
     - A soft tube is surgically placed in your abdomen and the inside lining of your abdomen (the peritoneum) acts as a filter.
     - Fluid (dialysate) is put into your belly through the tube and later drained out after a period of time.
     - The fluid that is drained contains the excess fluid and waste normally removed by the kidneys.
     - This needs to be done several times a day and is done by the patients themselves at their home or work.



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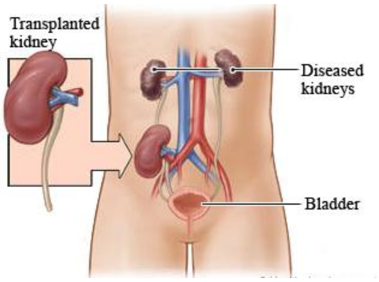
2. **Kidney Transplant** –
   - A healthy kidney, through surgery, is placed into your body. A kidney can be from a person who has died and chosen to donate or a living person with two healthy kidneys and has chosen to donate one.
   - This kidney will replace the functions of your own kidneys. Only one healthy kidney is needed to replace two failed kidneys.
   - For many people, a kidney transplant can offer more freedom and a better quality of life compared with dialysis.



Getting a Kidney Transplant – What is involved?

A kidney transplant is often the treatment of choice for kidney failure. For some people, the risks of transplant may outweigh its benefits when compared with dialysis. It is important for each kidney transplant candidate to complete thorough medical and psychosocial evaluations to determine if there are any factors that may increase risks associated with major surgery and recovery, lifelong immune suppression medications and their side effects, as well as survival after transplantation.

There are four parts to the evaluation process

1. Referral to a Transplant Center

- Your nephrologist or PCP can refer you to a transplant center for an evaluation when your kidney function is declining or you are already on dialysis. You can also contact a transplant center on your own and ask to be evaluated.
- Your medical records need to be sent to us to:
    - Understand your current medical conditions and how they might affect transplant.
    - Review your medical and surgical history.
    - Review your routine health maintenance history.
- Our financial coordinator will review your health insurance details to ensure coverage for surgery, medications, and office visits.

2. Physical Evaluation

- Transplant evaluations can take several hours so please plan to be at the transplant center for at least half a day.
- You will meet a transplant surgeon and a transplant nephrologist separately to thoroughly review your medical history and physical examination.
- You will meet your transplant nurse coordinator to learn more about transplant and next steps.
- You will have multiple tubes of blood drawn
- You may have an EKG done
- The Transplant Team will often ask for additional tests to evaluate:
    - your other organs and blood vessels
    - your risk for cancers
    - your risk for infections
    - other parts of your medical history that may be affected by transplant

We try to reduce the number of trips to the hospital needed to complete these studies, but a complete evaluation may require more than one visit.

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

3. Psychosocial Evaluation

- 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. Candidacy Decision

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

Please let your nurse coordinator know if you have any changes with your medical condition or if you are having any medical tests while you are being evaluated or awaiting transplant.

Please ask your medical care teams to share any results with us.

Fax 617.525.0431, to the attention of your nurse coordinator.

You will have many blood tests as part of your kidney transplant evaluation and continued candidacy. Some of these tests will be sent to the Tissue Typing Lab to:

1. **Confirm your blood type**

   It is important that you and your kidney donor have compatible, blood types.

2. **Determine your Human Leukocyte Antigen (HLA) type**

   Your HLA type is a made up of six unique genetic markers found on your blood cells. These proteins are present on an individual's cells and allow their immune system to recognize 'self' from 'non-self.'

   Your potential donor(s) will also have their HLA type determined. The more similar the HLA type is between a donor and recipient, the closer the "match." Closer matched kidneys MAY have better long-term outcomes but if a kidney is not matched at all, it can still last a long time and does not prevent donation.

3. **Test 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.*
- 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%.
- 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.
- The lower the number, the fewer the antibodies are in your blood. Individuals with a high PRA are often termed '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 can change over time.

4. **Crossmatch**

   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 *SPECIFIC* donor kidney. This test is called a CROSSMATCH.

NOTE: IT IS IMPORTANT TO TEST YOUR PRA AND CROSSMATCH EVERY MONTH WHILE ACTIVE ON THE TRANSPLANT WAIT LIST

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

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

- A healthy, living person donates one of their kidneys to a person whose kidneys are not functioning properly. The donor will be able to continue a healthy life with one kidney.
- Living donation is preferred because it offers the best opportunity for the best quality kidney and the shortest waiting time.
- Each living donor is thoroughly evaluated to ensure that the removal of a kidney will not likely harm his or her health in the future. This process is done by a different doctor than the one who evaluates you.
- There is no guarantee that someone who wants to donate a kidney will be able to do so.

If there is someone interested in donating a kidney to you, we can help you set up a microsite for your personalized donor link. Microsite is a tool we use to help our recipients look for potential living donors. Please ask your RN coordinator to get one set up for you.

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:
BWH is a Center of Excellence with the National Kidney Registry (NKR). If your potential living donor is not compatible with you, they can participate in a swap or paired kidney exchange to donate on your behalf. Please visit https://kidneyregistry.org to learn more about living donation and paired kidney exchange.

Your transplant team can discuss if being part of a kidney exchange is a good option for you.

2. Deceased donor transplants

- If you do not have a living kidney donor, you will be placed on the national wait list for a deceased donor kidney
- Deceased donor kidneys are donated by a person who has died and has met the criteria for brain death or circulatory death. This person previously indicated their desire to donate by registering their consent at https://www.donatelife.net/ or 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. A nationwide program has been 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.
- On December 4, 2014, the United Network for Organ Sharing (UNOS) implemented a new allocation system and classification for deceased donor kidneys known as the Kidney Donor Profile Index (KDPI).

- The KDPI is a numerical measure that combines ten dimensions of information about a donor, including clinical parameters and demographics, to express the quality of the donor kidneys relative to other donors.
- The KDPI score is based on donor age, height, weight, ethnicity, whether the donor died due to loss of heart function or loss of brain function, stroke as cause of death, history of high blood pressure, history of diabetes, liver function and serum creatinine (to measure kidney function).
- The reference population of donors includes all deceased donors in the U.S. from whom a kidney was recovered for the purpose of transplantation during the prior calendar year.
- Lower KDPI values are associated with increased donor quality; higher KDPI values are associated with lower donor quality. The KDPI score ranges from zero to 100 percent. The score is associated with how long the kidney is likely to function when compared to other kidneys.

The higher the KDPI score, the shorter the time the kidney is predicted to last. Waiting times for kidneys with a KDPI greater than 85% are shorter. By agreeing to receive one of these kidneys, you will increase the chances of being transplanted sooner. Please note that any kidney may improve your health and longevity compared to staying on dialysis

The Kidney Donor Profile Index >85% Waitlist

The KDPI allocation system is under the direction of UNOS and helps certain types of recipients receive transplants in a timelier fashion.

The KDPI >85% waitlist is a list within the larger UNOS Waitlist. The criteria for these donor kidneys are slightly less stringent. Candidates who agree to receive a KDPI >85% kidney are ***also*** eligible to receive a kidney with a lower KDPI.

Appropriate candidates for the KDPI >85% list are usually older or have medical problems, which warrant some urgency to transplant. Registration on the KDPI >85% list would occur only after your nephrologists and surgeon have thoroughly discussed the pros and cons with you, and agree that you are an appropriate candidate for this type of transplant.

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.

The amount of time that you wait for a kidney depends on several 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 living donors while you are on the deceased donor transplant waitlist.

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.

What does waitlist "active" status mean?
You are on the registered UNOS waiting list, gaining wait-time and will be eligible to be transplanted should an organ donor become available for you.

What does waitlist "inactive" status mean?
You are on the registered UNOS waiting list, gaining 'wait-time' but you are NOT eligible to be transplanted or receiving organ offers until your status is changed to active.
Examples of why you might be "inactive":

- Your kidney function is declining, but stable, and you do not need dialysis yet.
- You have a current medical problem which needs sorting out.
- You are working on getting the proper insurance to cover transplantation.

Don't worry; we will work with you on these issues to change your status to "active" as soon as possible.

Once you are "active" it is very important for us to know how to get in touch with you at any time, day, or night. If your contact information changes, call as soon as possible: 617-732-6866.
We need to have all your phone numbers: home, work & cell. Please keep your cell phone always charged and on.

You may go through changes to your medical changes while you are awaiting a transplant. Certain changes or hospitalizations could change your status on the wait list. It is vital that you contact your nurse coordinator with any health changes to ensure that you are in the best condition for your transplant. You should contact your nurse coordinator if you are:

- taking antibiotics or have an active infection.
- getting a blood transfusion.
- admitted to a hospital.
- having a significant change in your health status.
- changing your insurance coverage.
- updating your contact information (such as phone number or address).
- changing your support person or plan.
- planning to travel away from home.

Taking care of your health is very important while waiting for a transplant. It is expected that you will take all your medicine as told to by your doctor, follow any plans for diet and exercise, attend all doctor's appointments and, if on dialysis, attend all sessions. We rely on your local doctors to address routine health issues. This may include diabetes, minor infections and illnesses, and regular health maintenance.

Your preventive healthcare is extremely important too. Continue to work with your health care specialists and primary care provider for recommended age-related screenings and vaccines to prevent disease. The American Cancer Society regularly reviews the science and updates screening recommendations when new evidence suggests that a change may be needed. Completing these tests and vaccines will help to ensure that you are in the best condition for your transplant. All results should be forwarded to us, your Transplant Team at fax: 617.525.0431.

Please review your immunization record with your primary doctor and your transplant coordinator.

Vaccine	When and Who to Vaccinate	Notes
*COVID-19**	• All transplant candidates • One or more doses of updated formula	• Persons who are immunocompromised are special situations for additional vaccine • An mRNA product is preferred
Influenza	• All transplant candidates annually	• If immunosuppressed, injectable 'high-dose' influenza vaccine, which is **not** live
Respiratory syncytial virus (RSV)	• 1 dose • Above age 60 due to ESRD Dx	• At any time, but best in late summer and early fall (August – October)
Tetanus & Diphtheria (Td) / Pertussis (Tdap)	• If never received Tdap, should get a dose of Tdap. • If it has been >10 years since last tetanus booster	• Giving Tdap < 2 years from last tetanus booster can result in a severe local reaction
Measles Mumps Rubella (MMR)	• If lacking immunity to measles, mumps, or rubella on IgG testing • 2-dose series	• **Live vaccine** MMR contraindicated for immunocompromised persons • Single dose, followed by serological reassessment ~3 weeks after vaccination; if still seronegative, can give second MMR dose 4 weeks after first vaccination.
Varicella [VAR] (Varivax)	• No evidence of immunity to varicella on IgG testing • 2-dose series	• **Live vaccine** VAR contraindicated for immunocompromised persons • If previously received 1 dose, give 1 dose at least 4 weeks after first dose
Zoster, recombinant [RZV] (Shingrix)	• A history of chicken pox • Age 50 years or older • If varicella titers are positive in the absence of previous varicella vaccination	• Two vaccine series given at 0 and 2-6 months • Persons who are immunocompromised are special situations for vaccination age 19-50.
Human Papilloma	• Males or females between the	• Three vaccine series given at 0, 1-2

Virus (Gardasil 9)	ages of 9-26 years; also MSM >26 years of age	months, & 6 months
Pneumococcal (Vaxneuvance [PCV15], Prevnar 20 [PCV20], Pneumovax 23 [PPSV23])	• If never vaccinated • If patient only received one dose of PCV15, a dose of PPSV23 should be given at least 1 year after the PCV dose. • If >5 years since previous PPSV23 • 1 dose PCV20 or PCV21	• Persons with chronic renal failure are special situations for vaccination age 19-64. • 1 dose of PCV20 is adequate • A minimum interval of 8 weeks between PCV15 and PPSV23 can be considered • If pt has received a previous dose of PCV13 or PPSV23, see guidance^
Hepatitis A	• If not previously vaccinated or exposed	• Two or three dose series, depending on the vaccine manufacturer
Hepatitis B†	• If surface antibody (HBsAb) and surface antigen (HbsAg) are negative • 2- or 3- or 4-dose series depending on the vaccine manufacturer	• Persons on dialysis are special situations for completing a 3- or 4-dose series with Dialysis Formulations (higher dose) • Administration schedule: ○ 2 vaccine series (Heplisav-B - preferred): ○ 0, 4 weeks ○ 3 vaccine series (Engerix-B, PreHevbrio, or Recombivax-HB) ○ 0, 2, 4 weeks OR ○ 0, 1, 4-6 months • Check HBsAb 2-4 weeks after vaccine series completed • If HbsAb negative, repeat series

* COVID-19 vaccination is indicated for all solid organ transplant candidates regardless of prior SARS-CoV-2 infection. https://www.cdc.gov/vaccines/covid-19/downloads/COVID-19-immunization-schedule-ages-6months-older.pdf

^ https://www.cdc.gov/vaccines/vpd/pneumo/downloads/pneumo-vaccine-timing.pdf

† Hepatitis B virus vaccination is indicated for anti-hepatitis B surface antibody (anti-HBs)-negative solid organ transplant candidates.

Vaccination of transplant candidates shows improved outcomes.

Our goal is to enhance positive patient outcomes by patients receiving vaccinations recommended by the Centers for Disease Control and Prevention (CDC) Advisory Committee on Immunization Practices (ACIP) before the time of their transplant. Certain vaccines are essential before transplantation and are required to be active on the Transplant Wait List at Mass General Brigham. Required vaccines should be administered prior to transplantation with enough time to allow for an immune response and to manage vaccine-related side effects that may lead to postponing transplantation (e.g., fever after vaccination).

Reference

Centers for Disease Control and Prevention Advisory Committee on Immunization Practices.	https://www.cdc.gov/vaccines/hcp/acip-recs/index.html
ACIP Vaccine Recommendations and Guidelines	https://www.cdc.gov/vaccines/schedules/downloads/adult/adult-combined-schedule.pdf

Section 3: At the Time of Your Transplant

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

The first successful kidney transplant was performed by Dr. Joseph E. Murray and his team at Brigham Hospital, now Brigham and Women's Hospital, in 1954. The surgical procedure for kidney transplantation has been improved over the years. Patients often have many questions about the transplant operation.

Frequently asked questions:

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

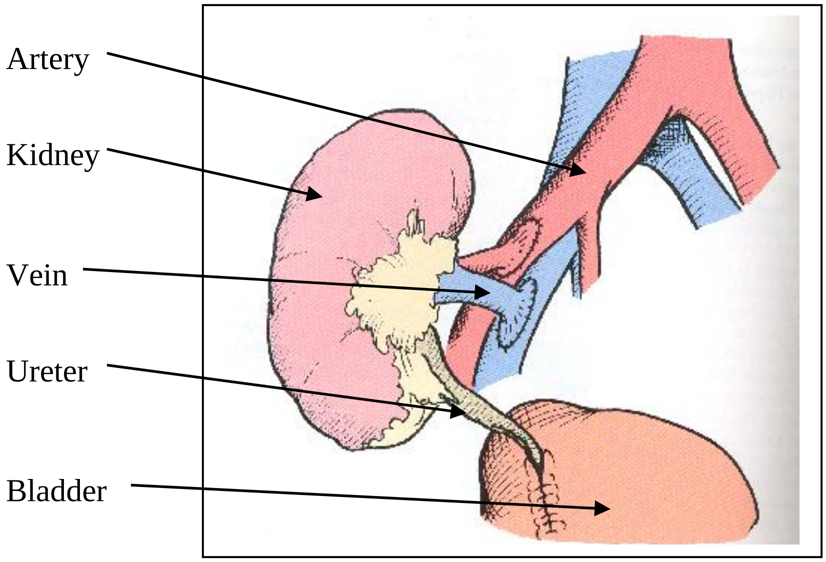
The transplanted kidney will be placed on the right or left side of your lower abdomen.

Technical aspects

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

How long will the surgery take?

The operation typically takes about four hours. The procedure is done under general anesthesia, so you will not be awake during the surgery and a machine will help you breathe. A member of the anesthesiology team will always be monitoring your heart rate, blood pressure, and blood oxygen levels throughout the procedure.



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 are situations in which you may benefit from the removal of one or both of your own 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 specialized floor with care providers experienced in kidney transplantation. You will have your own room. 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.

<u>Do complications occur that are related to the surgery?</u>

Unfortunately, complications can occur during or after any surgery. 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 (can occur about 2-5% of the time):

This is a rare but severe complication. Thrombosis can stop blood flowing into the kidney. We follow such an event very closely. We perform an ultrasound of the kidney routinely to make sure that no clots have formed, and blood is flowing appropriately throughout the transplanted kidney.

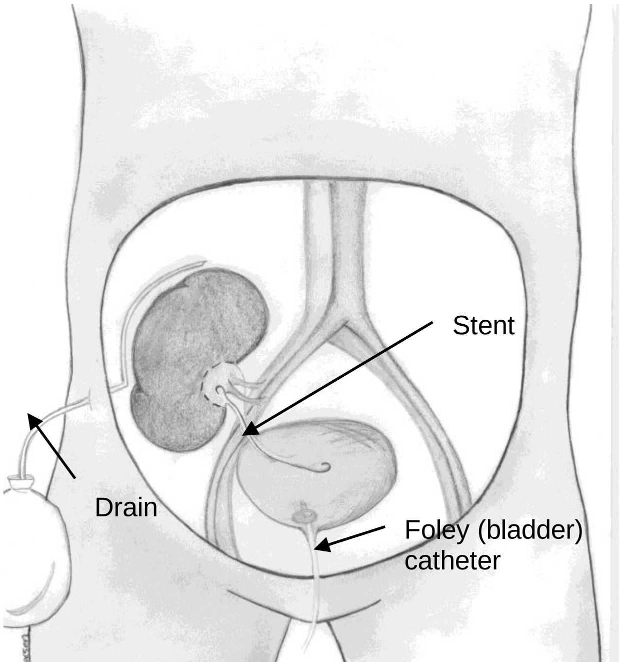
Leakage from the connection of the ureter to the bladder (can occur about 4-6 % of the time):

We try to avoid this complication by placing a ureteral stent. 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. Data has shown that this may help reduce the risk for a leak.

Any complication that can happen after any type of surgery can also happen after a kidney transplant. These complications may include:

- Bleeding
- Local (e.g., skin or wound) and systemic (e.g., urine or lung) infections.
- Blood clots in your legs, which can travel to your lungs. We encourage you to walk around as soon as possible after surgery to decrease this risk.
- Need for additional surgery

<u>Stents, Drains, Staples: When will they be removed?</u>



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 between the transplanted kidney through the ureter and into your bladder to protect the newly made connection between the transplant ureter and your bladder as it heals.

This stent will be removed approximately 6 weeks after the surgery during a cystoscopy. The procedure is similar to having a foley catheter placed.

Drains:

You may have a temporary drain collecting fluid around your transplanted kidney placed. The drain will be removed once it collects less than 30 cc in a day for 3 consecutive days. Fluid collections can form if a drain is removed too soon.

Staples:

If your incision is closed by staples, they will be removed approximately 14 days after surgery.

Foley Catheter:

We place a Foley catheter in your bladder once you are under anesthesia before surgery starts. This will stay in your bladder for at least 4 days after surgery to decompress your bladder and help us closely monitor how much urine you are making.

How long will I need to stay in the hospital?

Most patients stay in the hospital for 5 to 7 days after surgery. During this time, we are closely monitoring your new kidney and adjusting your new medications.

How long is the recovery period?

Most likely you will be back to your normal activity level in about 4-6 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 by a transplant nephrologist for lab work and follow up. These appointments will be scheduled for you at the time of your discharge. The appointments will become less frequent with time if you are doing well.

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 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, follow your fluid intake, your urine output, and your weight.
- For more details on monitoring your transplanted kidney, please see Section 7 of the Clinical Visits and Post-Transplant Guidebook. You will document these there.

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….**
Soaking in water	Avoid soaking in a bath for four weeks to prevent infection and allow for complete healing, also avoid hot tubs, swimming, saunas, etc. for at least 4 weeks
Taking a shower	You can resume showering immediately, but allow the water to run over your incision and avoid scrubbing. Avoid having the water hit it directly. Dry the incision completely by gently patting instead of rubbing.
Lifting	Lifting, pulling, or pushing more than 15 pounds (about the weight of a bag of groceries) for 6 weeks to allow your inner tissues and muscles time to regain their previous strength
Walking/Exercising	You can resume walking immediately for short distances, but don't allow yourself to become overly tired or dehydrated. Swimming and moderate exercise is generally fine after 6-8 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

Please call the transplant clinic nurses (DAYTIME) or the renal transplant attending doctor on call (evenings and weekends ONLY) if you experience any of the following:

- Temperature >100.5 F
- Large decrease in your urine output (for example < 4 cups per day)
- Signs of infection (redness, swelling, increased pain, discharge)
- 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 heartbeat
- 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
- Blood clots in your urine
- Decrease in urine production or no urine production

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 Transplant Surgeon
- Your Attending Transplant Nephrologist
- Renal Transplant Pharmacist
- Transplant Social Worker
- Physical therapy
- Post-Transplant Nurse Coordinator

You should feel comfortable with:

- Your medication instructions
- Wound care and dressing changes, if necessary
- Managing your foley catheter, if necessary
- Monitoring your blood sugar, 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 your new medications, as delivered to your room by the local specialty pharmacy
- 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

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:

- Your Transplant Handbook
- Up to date medication list
- 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).

The follow-up schedule is intense for the first few months. Labs, ultrasounds, and biopsies are done to monitor your kidney transplant. Rejection can happen when your body's immune system attacks your new organ. A biopsy may be done to evaluate for rejection. During a biopsy, pieces of tissue are taken from the inside of your organ and studied under a microscope. If a biopsy is done because your organ is not showing normal function, it may be somewhat urgent. You may need to make plans to come to BWH without much warning. The best way to prevent rejection is to take all your medications as prescribed.

After your transplant, you will be on many medicines. You will be on some of them for the rest of your life. Others will be stopped after a few months. These medications may be used to:

- Prevent rejection
- Prevent infections
- Control blood pressure
- Control cholesterol
- Prevent bone loss
- Provide you with extra vitamins and minerals
- Control blood sugars

You will need to know what medicines you are taking, why you are taking them, and the dose prescribed for you.

Not taking your medicines correctly can lead to rejection or health problems.

Maintenance Medications: Tacrolimus Immediate Release (Prograf®, FK506, FK) or Extended Release (Envarsus XR®)

generic name

Tacrolimus - this medication is available as a generic, unless you receive the extended-release formulation and then it is available as brand only

Trade Name

Prograf® (immediate release); **Envarsus XR®** (extended release)

What is Tacrolimus?

❖ Tacrolimus suppresses the immune system, which is necessary in kidney transplant patients to prevent organ rejection.

How long will I need to take Tacrolimus?

❖ You will need to take Tacrolimus for as long as the transplanted kidney remains working.

What are some of the more common side effects of Tacrolimus?

- Increased creatinine: Tacrolimus, especially at high levels, may increase your creatinine. If this occurs, it may be necessary for us to decrease your dosage. This is one of the major reasons why we will check your Tacrolimus levels so often.

- Increased blood sugar: some patients who are not diabetic before the transplant may develop difficulties controlling their blood sugars after the transplant. We often have to administer oral medications and sometimes insulin to help control these high blood sugars. This side effect is one that may go away with time.

- Increased potassium: elevations in potassium levels can be seen in patients who are receiving Tacrolimus. Potassium levels are monitored every time labs are drawn. We can manage high potassium levels by lowering the Tacrolimus dose (if possible) or administering a medication that acts to lower the potassium levels.

- Decreased white blood cell count: it is important that we maintain your white blood cell count, as it is one way to prevent you from getting an infection.
- High blood pressure: high blood pressure is very common after transplantation. Tacrolimus can contribute to this. Several medications are available for use in transplant patients with high blood pressure.

- High cholesterol: high cholesterol is very common after transplantation. Tacrolimus can contribute to this. Several medications are available for use in transplant patients with high cholesterol.
- Stomach upset and/or diarrhea: stomach upset, and diarrhea is common side effect with most medications.

- Hand tremor: Tacrolimus may cause a fine hand tremor in transplant patients and usually occurs in patients with a high blood level. This tremor may go away with time, but if it occurs, please let one of the transplant team members know and, if possible, we can lower the Tacrolimus dose or convert you to the extended-release version which has shown to cause less hand tremors.

- Hair loss: hair loss occurs in about 20% of patients receiving Tacrolimus. This side effect is generally seen within the 3 months post-transplant, and generally resolves on its own after approximately 6 months.

Maintenance Medications: Mycophenolate (Myfortic®, MPA)

generic name

Mycophenolate sodium - this medication is available as an enteric-coated generic

Trade Name

Myfortic®

?

What is Mycophenolate?

- Mycophenolate suppresses the immune system but works differently compared to Tacrolimus.

How long will I need to take Mycophenolate?

- You will need to take Mycophenolate for as long as the transplanted kidney remains working.

What are some of the more common side effects of Mycophenolate?

- Decreased white blood cell count: it is important that we maintain your white blood cell count, as it is one way to prevent you from getting an infection.

- Decreased white blood cell counts are common in patients taking Mycophenolate.

- If this side effect occurs, it may require that we reduce your Mycophenolate dosage.

- Stomach upset and/or diarrhea: stomach upset, and diarrhea is the most common side effect with Mycophenolate. To help prevent this, we prescribe the enteric coated version and will have you take Mycophenolate with food. If this side effect occurs despite taking the Mycophenolate with food, we may split up the doses of this medication (instead of two times a day, we may have you take smaller doses three or four times a day) or lower the total daily dose. Some patients who cannot tolerate the stomach upset or diarrhea from Mycophenolate may be changed to another transplant medication that may cause less stomach or bowel irritation.

Maintenance Medications: Prednisone

generic name

Prednisone

Trade Name

- This drug is available as a generic and is no longer available as a trade name product.
- Many pharmaceutical companies make a generic version of this medication; therefore, the pills are available in several different shapes and colors.

What is Prednisone?

- Prednisone suppresses the immune system but works differently compared to both Tacrolimus and Mycophenolate.
- Prednisone is known as a steroid. You may be familiar with this medication, as it can also be used to treat inflammation and pain.

How long will I need to take Prednisone?

- The transplant team will let you know how long you will be taking this medication.
- Some patients need to take this medication for only a few days, while others need to take it for as long as the transplanted kidney is working.
- Determining whether you can stop Prednisone after the transplant is something that your transplant surgeon and nephrologist with discuss with you.

What are some of the more common side effects of Prednisone?

- It is important to note that most of the side effects listed below are seen in patients who continue taking prednisone after the transplant. Most patients who are taken off prednisone 7 – 28 days after transplant experience few side effects from this medication.

- Increased blood sugar: some patients who are not diabetic before the transplant may develop difficulties controlling their blood sugars after the transplant. We often must administer oral medications and sometimes insulin to help control these high blood sugars. This side effect is one that may go away with time.

- High blood pressure: high blood pressure is very common after transplantation. Prednisone can contribute to this. Several medications are available for use in transplant patients with high blood pressure.

- High cholesterol: high cholesterol is very common after transplantation. Prednisone can contribute to this. Several medications are available for use in transplant patients with high cholesterol.

- Stomach upset and/or diarrhea: stomach upset, and diarrhea is common side effect with most medications. Taking prednisone with food may help this side effect.

- Weight gain: prednisone can cause patients to gain weight by two mechanisms. First, it makes people hold onto water; therefore, the more water they hold onto, the heavier they get. Second, this medication can cause an increased appetite in approximately 3% of patients.

- Bone loss: osteoporosis is a rare, yet serious side effect of prednisone. Even as little as one dose of prednisone can cause bone loss. If you are maintained on prednisone, it is important to have your bone mineral density checked by your primary care physician. This test should be performed every two to three years in patients who remain on prednisone after the transplant.

- Night sweats: some patients may experience night sweats while receiving prednisone. This side effect usually takes place with higher doses and goes away with time.

- Mood changes: every night we make a similar drug to prednisone in our bodies when we sleep called cortisol. Cortisol helps us deal with stress and our emotions. When prednisone is prescribed after the transplant, it is not uncommon to see patients develop rapid mood swings (i.e., happy to sad, laughing to crying). This side effect generally disappears after about 5 days of being on the prednisone. It is important that if you have had problems with depression or other psychiatric illnesses in the past that you let the transplant team know if the prednisone is making it worse.

- Cataracts: you will be asked to make yearly visits to your eye doctor to make sure that this side effect does not take place.

- Acne: a small percentage of patients may develop acne after the administration of prednisone. Good skin hygiene is the best prevention for this, and over-the-counter acne medications may be helpful, but please consult with a transplant team member before starting any medications for acne.

Antibiotic – Sulfamethoxazole/Trimethoprim (Bactrim®, SMZ/TMP)

- As mentioned above, the most common antibiotic used to prevent *Pneumocystis* pneumonia is called Sulfamethoxazole/Trimethoprim, which is a sulfa-drug.

- One of the big benefits of taking Sulfamethoxazole/Trimethoprim is that it is also effective at preventing urinary tract infections and infections around the surgical incision sites.

generic name **Sulfamethoxazole/Trimethoprim** (also known as SMZ / TMP) - this drug is available as a generic medication.

Trade Name **Bactrim®**

What are some of the more common side effects from Sulfamethoxazole /Trimethoprim?

- Increased creatinine: Sulfamethoxazole/Trimethoprim may increase your creatinine. If this occurs, it may be necessary for us to discontinue this medication early or start you on a different antibiotic.

- Stomach upset and/or diarrhea: stomach upset, and diarrhea is common side effect with most medications. To help prevent this, we will ask you to take this drug with food.

- Increased potassium: elevations in potassium levels can be seen in patients who are receiving Sulfamethoxazole/Trimethoprim. Potassium levels are monitored every time labs are drawn.

- Decreased white blood cell count: it is important that we maintain your white blood cell count, as it is one way to prevent you from getting an infection.

- Sensitivity to the sun: this medication can make your skin more sensitive to the sun and more likely to develop sunburn, even in the winter. Please wear sunscreen when you go out into the sun to help prevent sunburns.

- Rash: rarely, patients receiving Sulfamethoxazole/Trimethoprim can develop a rash. If this happens to you, please call your one of the transplant team members. You may need to be switched to another antibiotic.

Antibiotic – Atovaquone (Mepron®)

- For those patients that are allergic to sulfa-drugs, we will use Atovaquone to prevent *Pneumocystis* pneumonia, which is just as effective, but does not cause the allergic reactions that are seen in some patients who take sulfa-drugs.

- Patients that need to take Atovaquone after transplant will also be given antibiotic called Cephalexin or Levofloxacin. This is to help prevent urinary tract infections and infections around the surgical incision sites.

generic name **Atovaquone**

Trade Name **Mepron® -** this drug is not currently available as a generic.

What are some of the more common side effects from Atovaquone?

- Stomach upset and/or diarrhea: stomach upset, and diarrhea is common side effect with most medications.

Antiviral – Valganciclovir (Valcyte®)

- If either you or your donor has been exposed to CMV, then you will receive a medication called Valganciclovir, which is very effective at preventing CMV from causing an infection.

generic name **Valganciclovir**- this drug is available as a generic medication.

Trade Name **Valcyte®**

What are some of the more common side effects from Valganciclovir?

- Stomach upset and/or diarrhea: stomach upset, and diarrhea is common side effect with most medications. In order to help prevent this, we will ask you to take this drug with food.
- Decreased white blood cell count: it is important that we maintain your white blood cell count, as it is one way to prevent you from getting an infection.

Keeping the Commitment

For a transplant to be a success, you need to commit to the following things:

- Follow the treatment plan.
- Contact the transplant office about any new problems or symptoms related to your transplant or about any new medicines or tests you have.
- Take all prescription medicines as prescribed.
- Follow the diet and exercise plan advised by your doctor.
- Go to your appointments, clinic visits, lab draws, and biopsies.
- Do not abuse your body by smoking, drinking alcohol, or using nonprescribed medicines and herbals.

People can lead a healthy and normal life after transplant.

The main issues are the **increased risks of infection and rejection**. You will need to take hygiene precautions to avoid infections. You should wash your hands regularly and may need to wear a face mask. It may be best to avoid crowded places, areas with poor ventilation, or people who may be contagious.

The risk of rejection is greatest the first 6–12 months after transplant.

When rejection occurs, we need to adjust your medicines to decrease your immune system further. These medicines have side effects that can cause new health concerns. High blood pressure, high cholesterol, diabetes, and osteoporosis can occur. Most of these side effects can be treated. Diet, exercise, and how well you follow your treatment plan all affect how you will be able to manage the side effects.

The Transplant Team will manage your transplant medicines and address any issues about your transplant. You will also have a primary care provider and may see other specialists as needed.

Open communication with your team will help everyone work together. We want you to live a healthy life after transplant!

Writing to your donor family is a personal decision

You may want to write to the donor family to thank them. Many donor families have said that a card or personal note from a recipient of their loved one's kidney offers them comfort.

What you might write about

- Talk about yourself, your job, hobbies, interests, and family. We ask 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?

Mail your letter to New England Donor Services (NEDS)

- When closing your card or letter, sign your **first name only**.
- Place your card or letter in an **unsealed** envelope
- **On a separate piece of paper**, write your full name, transplant center, organ received, date of the transplant, mailing and email addresses.
- Place these items in another envelope and mail to:

New England Donor Services
ATTN: Aftercare Services
60 First Avenue
Waltham, MA 02451
If you prefer, email: AC@neds.org

The NEDS Aftercare team will forward your letter to the family. You may or may not receive a letter 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.

- To learn more about the NEDS Aftercare donor family and recipient guidelines and connect with the donor's family by "Sending a Care Card" electronically via the NEDS Aftercare Specialist, visit: https://caringconnectionsneds.org/connect/
- For information about the NEDS Aftercare donor family and recipient guidelines and connect with the donor's family by "Sending a Care Card" electronically via the NEDS Aftercare Specialist, visit: https://caringconnectionsneds.org/connect/
- If you still have questions, contact NEDS Aftercare Services at: (781) 373-7945

If you receive your kidney from a living kidney donor, you could thank them too!

- Complete the same process above
- Give your letter / message to the Brigham Living Donor Center

ATTN: Living Donor Nurse Coordinators
15 Francis St, PBB 215; Boston, MA 02115
If you prefer, email: bwhlivingdonoradmin@partners.org