Introduction to Transplant Evaluation Candidate Education

Assessing if transplant is right for you.

Kidney Transplant Program
Medical Arts Pavilion 2
FOR THE LOVE OF HEALTH™

We serve our neighbors as respectful, expert, caring partners in their health. We do this by creating innovative, effective, affordable systems of care that our neighbors value.
What to expect?

- Available medical records are being reviewed by clinical members of the transplant team.

- Today's live, virtual education session with information about kidney transplantation, associated risks & the evaluation process.

- Individual Telehealth sessions will be scheduled with a transplant social worker, financial counselor, registered dietitian & possibly transplant pharmacist.

- In office appointment with transplant nephrologist, transplant surgeon, transplant coordinator & transplant lab work.
Why are you here?

Objectives

✓ To see if kidney transplant is right for you by learning about the process, requirements & risks.

✓ To meet your transplant coordinator.

You will meet other members of the Multidisciplinary Team through Telehealth visits & our physicians at your in office visit.

Note: This visit does not mean you are automatically placed on the waiting list.
Question

Does an evaluation guarantee you a place on the waiting list?
Transplant RN Coordinators

- Guides you through the testing
- Shares information about testing
- Collaborates with other health care providers regarding your testing
- Main resource for support and answers
- Communicates the team’s decisions
- Point person while you wait for transplant
Transplant Nephrologists

- Will be seen at in office visit
- Trained as a medical kidney doctor or nephrologist
- Addresses blood pressure, electrolytes and other non-surgical issues related to transplant
- Helps to coordinate medical issues that may impact a kidney transplant
- Manages long-term immunosuppression in post transplant patients to optimize longevity of your kidney transplant
Transplant Surgeons

- Will be seen at in office appointment.
- Performs kidney transplant surgery.
- Determines if patients are suitable for surgery.
- Manages anti-rejection medications after transplant.
Transplant Social Worker

- Individual Telehealth consult with you & support person
- Directs you to resources for health/family issues
- Provides resources for recovery/rehabilitation
- Assists with insurance or medication problems
- Leads support group for patients
- Makes referrals to psychiatry or other counselors as needed
Financial Coordinator

- Individual Telehealth consult
- Reviews insurance
- Contact point for insurance changes
- Checks type of benefits for transplant and related medications
- Explains Medicare, Medicaid, DE Chronic Renal
- Do not forget to call us with any changes!
Transplant Dietitian

- Individual Telehealth Consult
- Assesses current nutritional status and compliance
- Provides individualized counseling based on patients' needs:
  - Weight loss/gain to meet BMI standards
  - Increasing protein to improve albumin
  - Pre-dialysis diet education
  - Modified diet to improve lab values (potassium/phosphorus, etc.)
  - Carbohydrate controlled diet
- Assists with diet changes post transplant
Transplant Pharmacist

- Individual Telehealth Consult
- Records and evaluates your allergies
- Reviews your medications (prescription and non-prescription)
- Explains the differences between current and post-transplant medications and the pharmacist’s role in your care after transplant
- Answers your medication questions
Spiritual or Pastoral Services

- Available during any phase of care
- During evaluation over the phone
- While waiting on the list
- During hospital admissions
- Post transplant

To contact pastoral services, call 302-733-1280 or ask one of the transplant staff for assistance.
Your Current Nephrologist

- While waiting on the list, you will still be cared for by your current nephrologist.
  - ✔ Dialysis
  - ✔ Hospital admissions

- Immediately after transplant, your care will be managed by the transplant team.

- After a year or so, your care will be shared by both the transplant team, your current nephrologist and primary care physician.
Transplant Cardiologist

- Seen prior to listing to assess candidacy for transplant
- Seen annually while waiting on the list to assess continued candidacy for transplant
- Seen in addition to your own cardiologist (if applicable)
You...

- Are the most important member of our team.
- Must be involved in your care.
- Should contact your coordinator with changes in phone numbers, addresses, & dialysis centers.
- Should contact your coordinator with changes in your health.
- Should ask that test results be faxed to 302-623-3825.
Treatment Options

Kidney transplant – preferred for those medically eligible

✓ Living donor (<1 year)
✓ Deceased donor (5-10 year wait; 60% waitlist mortality in 5 years)

Dialysis – a bridge to transplant for those medically eligible

✓ Hemodialysis
✓ Peritoneal Dialysis

Patient survival is better if you are transplanted than staying on dialysis*.

*Depends on age and other health conditions; and if medically cleared to be transplanted.
To be eligible for transplant...

On Dialysis (hemodialysis or peritoneal)

OR

Not yet on dialysis, but kidney function* or below 20%

* Measured by the estimated glomerular filtration rate (eGFR)
Transplant is NOT an option if...

- Severe heart disease without possibility of intervention.
- Other organ failure requiring transplant – can be referred to another program.
- Patients with irreversible essential organ failure.
- Current malignancy (cancer).
- HIV infection, AIDS, or active infection.
- Multiple medical problems making surgery unsafe.
Transplant may not be right for you if...

- Age > 75
- Significant blood vessel disease.
- Patients who are unable to care for themselves and are without a support person to help them.
- BMI > 38
- Patients without means to financially afford post transplant medications.
Transplant may not be right for you if...

- Patients with active illegal drug use
- Patients with psychosocial contraindications
- Patients with cancers that have been treated
- Patients with recurrent infections
- Tobacco abuse (smoking or chewing)
- Untreated sleep apnea / CPAP non-compliance
Why do I have to do testing?

- To ensure your safety!
- To protect you from possible post transplant medications side effects
- To make sure your blood vessels are healthy for transplant surgery
What tests do I need to be listed?

**Cardiac testing**

- ✓ To decrease risk of adverse events during or after transplant
- ✓ Ensure your safety

**Blood work**

- ✓ To decrease risk of adverse events during or after transplant (Includes viral testing)
- ✓ Ensure your safety

**Radiology**

- ✓ Chest X-ray
- ✓ CT Scan of the abdomen and/or ultrasound
What tests do I need to be listed?

Your primary care physician may help you coordinate possible other health maintenance testing (to be current)

- ✓ Mammogram for women over 40.
- ✓ Gyn / PAP exam for women of all ages.
- ✓ Colonoscopy for everyone over 50.
- ✓ Dental clearance to rule out infection and cancers.

Health maintenance needs to be completed within 3 months of transplant evaluation.
Testing must be complete!!

You will **NOT** be approved for transplant or added to the national waitlist until...

Testing is completed and results are received/reviewed by transplant team!

Wait time is key factor in getting a deceased donor transplant!

- Average waiting time is **5 – 10 years** in our region.
- Blood type plays a major role in how long you wait for a deceased kidney.
  - A  5+ years
  - O  6+ years
  - B  7+ years
If approved for transplant...

You will be notified and registered for the national waitlist.

- **UNOS: United Network for Organ Sharing**
  
  Federal agency that manages the process and information on all potential listed recipients throughout the U.S.

- **OPO: Organ Procurement Organization**
  
  ✓ “Gift of Life” is our local organ procurement organization
  ✓ Serving Delaware, southern NJ, eastern PA
  ✓ Notifies transplant centers in this region when a deceased donor organ becomes available
What is multi-listing?

You may list in other regions (OPOs) i.e., Maryland’s “Living Legacy”

Advantages

✓ Increases your chances to match with a deceased organ donor
✓ Could decrease your wait time for a deceased donor

Disadvantages

✓ You must travel to the kidney for transplantation as well as all of your postoperative care

There is no benefit in multi-listing within the same OPO region, since you would receive the same kidney offers.
Why is there a wait list?

Approximately 750,000 people in the United States have end stage renal disease.

- >100,000 people are on the kidney transplant waiting list. 
  *increasing every day.*

- >17,000 kidney transplants are performed each year.
  
  ✓ 33% are from living donors – *preferred*
  
  ✓ 67% are deceased donors

*Source: kidney.org (2016)*
Listing Status

**Listed Status 1 (active)** *This is your goal!*
- Testing is complete
- Ready for transplant AND to be offered a deceased donor kidney.

**Listed Status 7 (inactive)**
- Gaining time, but will not be called for a deceased donor organ offer

*Reasons why you may be listed status 7*
- ✓ Change in functional status
- ✓ Waiting 1-year post heart stent
- ✓ Something that **TEMPORARILY** makes you NOT a candidate for transplant
Types of Donors:
A True Gift

Living Donors

Deceased Donors

Living donor transplants

Types of donors

✅ Living related
✅ Living unrelated

Criteria for living donors

✅ Must be between 18 and 65 year old
✅ Must be healthy
✅ Must be willing and want to give
✅ Must have compatible blood types
Advantages for living donation

- You do not have to wait years at risk on a list.
- Shorter time between kidney removal and transplantation
- Kidney spends minimal time “on ice” waiting to be transplanted
- Planned surgery
- Better outcomes
Living donor evaluation

- Living donor has a different coordinator
- Ensures healthy enough to donate
- Blood and tissue typing performed to check for compatibility
- Donor testing ordered
Living donor transplants

- Can be challenging, but very fulfilling.
- The timing of the donation is determined by the donor.
- The transplant team cannot share information about the donor with you, such as why they were turned down as a donor or if they decided not to go forward with donation.
Do you have a living donor?

Anyone who wants to be or could be a living donor should start by talking with their primary care physician to ensure age appropriate testing is up-to-date.

- ✔ Annual physical with primary care or family physician.
- ✔ Mammogram for women over 40
- ✔ Gyn exam for women
- ✔ Colonoscopy for anyone over 50
- ✔ Vaccinations
Do you have a living donor?

<table>
<thead>
<tr>
<th>Recipient Blood Type</th>
<th>Donor Blood Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>A</td>
<td>A, O</td>
</tr>
<tr>
<td>B</td>
<td>B, O</td>
</tr>
<tr>
<td>AB</td>
<td>AB, O, A, B</td>
</tr>
</tbody>
</table>
Paired kidney donation programs

- An alternate way of receiving a kidney from a living donor, when you and your donor are not a match.

- You and your donor are entered into a paired donation program... if you both agree.

- We participate with NKR and UNOS paired donation programs.
  - National Kidney Registry
  - United Network of Organ Sharing
Deceased donor transplants

Organ are given a value based on the following information:

- Donor Age
- Hypertension
- Serum Creatinine
- Height
- Race/ethnicity
- Diabetes
- Cause of death-Stroke
- Weight

- Donation after cardiac death (DCD)
- High risk behaviors (PHS)
- Hepatitis C Status

*Only candidates who already have Hepatitis C can receive these kidneys*
Quality of donated kidney
Kidney Donor Profile Index (KDPI)

Typical estimated half life of transplanted kidney

<table>
<thead>
<tr>
<th></th>
<th>Living Donor</th>
<th>KDPI 0-20%</th>
<th>KDPI 21-85%</th>
<th>KDPI &gt;85%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years</td>
<td>12.48</td>
<td>11.44</td>
<td>8.9</td>
<td>5.6</td>
</tr>
</tbody>
</table>

Best Overall  | Best Deceased Donor | Better | Good
KDPI categories…“Car story”

**KDPI 0 – 20%**
Allocated to patients those with longest expected post transplant survival

**KDPI 21 – 35%**
Allocation to pediatrics, then according to wait time

**KDPI 36 – 85%**
Allocation according to wait time

**KDPI > 85%**
Allocation to those who will accept kidney offers from middle aged donors with known prior health issues.
KDPI > 85 Kidney

- “Not quite ideal” kidneys
- Separate waitlist for recipients who sign a consent to consider offers
- Kidney survival rate is typically lower than with younger, healthier donors but . . .

If you are over 40, your survival rate is better than what it would be on dialysis!
Donation after cardiac death (DCD)

- Donor fails to meet the criteria for brain death.
- In order to be declared deceased, the donor’s heart must stop beating.
- Donor is removed from life support before kidneys are removed.
- 40% chance of delayed graft function, but kidneys will recover.

*You may need dialysis for a short time after your transplant*
Directed donation option

- If someone dies in a hospital under certain conditions, and their family is aware that you are on a kidney transplant list... *then they can ask that you be given the kidney.*

- Donor must be blood and tissue type compatible.

- Kidney can come from anywhere in the United States.
Public Health Services (PHS) increased risk donors

- All PHS donors are tested for HIV and hepatitis BEFORE you are called with the organ offer.

- Organs coming from donors that meet the criteria of the Public Health Services have increased risk for:
  - Sexual behaviors
  - Drug use
  - Tattoos/body piercings
  - Imprisonment
  - Greater than 10 blood transfusions
  - Travel out of the U.S.

- You will be told if kidneys are coming from donor with increased risk.

- You have the right to accept or not accept the offer.

1/3 of deceased donors are considered PHS high risk.
How are organs offered?

- 24/7/365 process managed by OPO and UNOS.
- The OPO ("Gift of Life") notifies UNOS.
- UNOS generates a new list for each kidney offered.
- Our surgeons first review the donor information.
- Patients are then notified by the transplant coordinator.
When a kidney becomes available

- We have **1 hour** to reach you by phone!
- Keep your contact information updated with us.
- **Answer the phone!**
  - Ensures us that you are available.
  - We ask questions about your health.
  - We discuss the offer with you.
  - You decide, if you want the kidney or not.
When a kidney becomes available

- You may receive **many offers** before you are transplanted.

- There are **many recipients** offered each organ:
  - ✓ Primary means you are first on the list.
  - ✓ Back up means you are not the first person in line.

- You will be at a different place in line for each kidney offer.

- Crossmatch to see if you are compatible with the donor.
No such thing as “Top of the List”

Order of the list changes with each organ offer based on:

- Donor’s blood type
- Crossmatch results
- Recipient's time on the list
- Recipient's state of health at the time
- KDPI of the donor

UNOS makes the ultimate decision for who gets the organ!
**Crossmatch tests if a recipient and donor are compatible.**

- Negative crossmatch is desired.
- A positive crossmatch means you cannot accept a kidney from this donor.
- Antibodies* can develop, so repeat crossmatch testing is sometimes required during evaluation of living donors and prior to all transplants.

*Antibodies are fighter cells against a specific protein in the donor*
Panel reactive antibodies (PRA)

- Recipient's serum is tested against a panel of cells from many people.
- Increases due to blood transfusions, prior transplants, abortions or pregnancy.
- A higher PRA makes finding a donor more difficult and impacts kidney survival.
Monthly blood samples

Once listed, a tube of your blood will be sent each month to the tissue typing lab to:

- Check for the presence of new antibodies (PRA)
- Be used for testing against any potential donors when available

Jefferson Hospital is our tissue typing lab.
Kidney transplant operation
Potential surgical issues/risks

- Bleeding
- Infection
- Fluid collections in wound
- Non-functioning kidney
- Clotting issues
- Urinary leak or blockage

Most complications can be corrected and happen infrequently.
What happens after transplant?

- Hospital length of stay
  - 3 – 5 days with living donor kidney
  - 4 – 6 days with deceased donor kidney

- Anti-rejection medications are started immediately
  - 2 – 3 medications for the life of the kidney.
  - Keeps your body from attacking the new kidney.
  - Side effects typically include nausea, vomiting & diarrhea.
  - Increased chance of infections and cancers.
  - Missed doses will increase the chance of rejection

- Follow-up exams and lab work
Post-transplant follow-up

- Transplant clinic follow-up in Medical Arts Pavilion 2
  - Short-term
  - Long-term office visits

- Thanking the donor family

- Continued care from transplant team for the life of the kidney

- It is extremely important to stay in contact with your transplant team...**even if you move.**
Medications after transplant

- Can be up to 10 different medications and 20-30 pills a day!
  - Prograf® (tacrolimus)
  - CellCept® (mycophenolate mofetil)
  - Nulojix® (belatacept) - monthly IV infusion

- Some are preventative to avoid infections (Bacterial, viral, fungal)

- Continue medications for blood pressure, cholesterol, diabetes.

- Anemia: may still need EPO shots
Potential medical problems

- **Cancer**
  - ✔ Skin: 50% @ 5yrs, 80% @10yrs
  - ✔ Kidney: your old ones
  - ✔ Post transplant lymphoproliferative disorder 1% risk caused by the EBV/Mono virus

- **Delayed Graft Function aka “sleepy kidney”**
  - ✔ You may need some dialysis for a short time

- **Rejection does not always mean you lose your kidney**
  - ✔ Biopsy at 3-months and 1-year
  - ✔ **Can be silent!** Frequent lab test are needed
What’s in your patient packet

- CCHS Kidney Transplant Program Brochure
- UNOS What Every Patient Needs to Know
- UNOS Facts & Figures
- UNOS Kidney Allocation Policy
- UNOS Multiple Listing and Waiting Time Transfer
- CCHS Learn More about Living Kidney Donation Brochure
- How to Find a Living Kidney Donor
- Frequently Asked Questions Packet

christianacare.org/kidneytransplant
General Questions?

Your specific questions can be addressed with your transplant coordinator or any staff member during your Telehealth consult.

If they are not, please let us know.