



Kidney Transplant Family Education Class

Introduction Module 1

Portland Transplant

Updated: 12/16/2020

Disclosures and Privacy

- No recording of this presentation will be allowed
- Please do not share personal medical/sensitive information as this is a group class.
- You may inform the RN if you'd like to follow up after class.
- In some instances, such as a pandemic, you may be selected for a potential transplant prior to having a face-to-face evaluation in Portland. As with every Veteran on the waitlist, there is a possibility that transplantation may not be safe at the time of face-to-face evaluation. You will have the opportunity to discuss this with your clinician after you arrive to Portland.



Portland Kidney Transplant

est. 2002



Kidney Transplant is Not a Cure

Kidney transplant is a treatment option!!

Other treatment options for end stage kidney disease.....

- Hemodialysis
- Peritoneal dialysis
- No treatment



When is Transplant Not Possible?

- Active infection (at the time of transplant)
- Active or recent cancer
- High chance of dying with surgery
- Anatomy that makes transplant technically impossible
- Morbid obesity
- Active/incompletely treated drug use, alcoholism, or psychosis
- Medical noncompliance



Benefits of Kidney Transplantation

- Quality of life
 - More like your own kidney than dialysis
 - Not as time consuming
 - More freedom to travel
 - Fewer dietary and fluid restrictions
 - Return to work or school
 - Improved fertility
- Quantity of life or how long you live



Risks of Kidney Transplantation

- Medications: life-long, many side effects, expensive
- Infections
- Cancer
- Rejection
- Coronary (heart) artery disease
- Surgical complications
- Financial concerns
 - Taking care of home while you are in Portland
 - Expenses while you are here
- Loss of dialysis support system



SRTR

Please see the SRTR handout in your packet for the most recent Program Summary Report

Patient survival:

- Portland VA 1 year expected patient survival
- National 1 year patient survival

Graft (kidney) survival:

- Portland VA 1 year expected graft survival
- National 1 year graft survival

See www.srtr.org for full program information



Transplant Recipient Evaluation

- History and Physical
- Laboratory
- Cardiac testing
- Chest X-ray
- Abdominal Ultrasound
- Dental Evaluation
- Dietary Evaluation
- Patient / Family Education
- Social Service / Financial Evaluation
- Immunizations
- For women: Pap/Mammogram
- For men: Prostate screening
- Colonoscopy
- Other testing as needed



Selection Conference

- Transplant Team Meeting
 - Transplant surgeons, transplant nephrologists, transplant coordinator, social workers and dietitians
- Review transplant evaluation results
- Determine if you are a transplant candidate
- Determine your risks with transplant
- Create a “to do” list / recommendations
- Transplant Coordinator communicates plan to you and your VA provider in writing

It is your responsibility to keep us informed of your progress!



Selection Conference Decision

- Accept
- Defer
- Decline



It is your responsibility to keep us informed of your progress!



When Do I Go on the List?

- Recommendations completed and reviewed by transplant team
- Current blood sample available in Portland
- UNOS paperwork completed for listing



Self Review: True or False

- Kidney Transplant is a cure: **True or False**
- It is up to me to let my transplant coordinator know when I complete my "to do" list: **True or False**
- If I decide not to take my medications or show up for dialysis it will not affect whether I am offered a donor kidney: **True or False**
- The pre-transplant process can be complicated and may look different for each person: **True or False**



Self Review: True or False

- Kidney Transplant is a cure: **False, it is a treatment option.**
- It is up to me to let my transplant coordinator know when I complete my "to do" list: **True**
- If I decide not to take my medications or show up for dialysis it will not affect whether I am offered a donor kidney: **False, past behavior is used to predict future behavior.**
- The pre-transplant process can be complicated and may look different for each person: **True**



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Up Next:

Kidney Transplant Family Education Class

The Science of Kidney Matching Module 2

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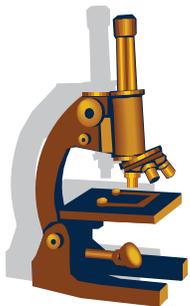
Kidney Transplant Family Education Class

The Science of Kidney Matching Module 2

Portland
Transplant

Updated 1/20/21

Immune System & Genetic Evaluation

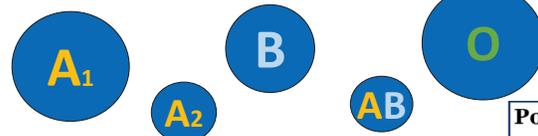


- Blood type
- Antibodies
- Crossmatch



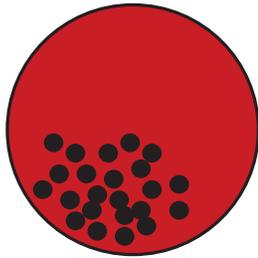
Blood Types & Compatibility

Recipient	Living Donors	Waiting List
O (46%)	O, ?A2	O
A (40%)	A, O	A
B (10%)	B, O, ?A2	B, ?A2, ?A2B
AB (4%)	AB, O, A, B	AB, A

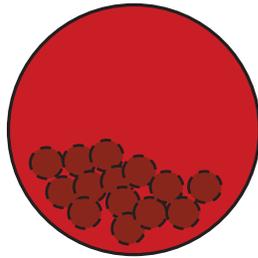


Cross Match – What are we looking for?

View of Cells through a Microscope



Negative



Positive – cell destruction



What Can Cause Positive Cross Matches? Why Would a Donor Not Be Compatible?

Antibodies: your body's reaction to donor's genetic markers

- Previous transplant
- Pregnancies
- Blood transfusions
 - Use white cell filter
 - No transfusion from potential donors

Your **PRA** measures these antibodies on a scale from 0 - 100%.



Monthly Blood Sample



Self Review: True or False

- A negative crossmatch is a good thing: **True or False**
- Since blood type O is the universal donor anyone waiting for a kidney can receive an O kidney : **True or False**
- The higher the level of antibodies, also known as a PRA, the more difficult it is to find a donor kidney: **True or False**



Self Review: True or False

- A negative crossmatch is a good thing: **True**
- Since blood type O is the universal donor anyone waiting for a kidney can receive an O kidney: **False, only living donors can donate to other blood types.**
- The higher the level of antibodies, also known as a PRA, the more difficult it is to find a donor kidney: **True**



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Up Next:

Kidney Transplant Family Education Class
The United Network for Organ
Sharing (UNOS) Deceased Donor
Kidney Transplant Waitlist
Module 3

Portland
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Kidney Transplant Family Education Class

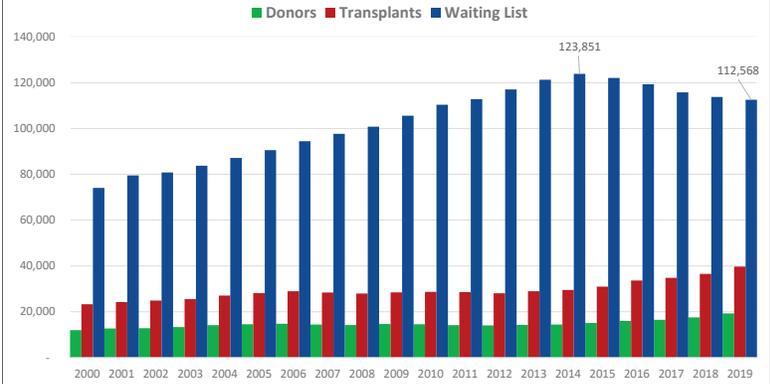
United Network for Organ Sharing (UNOS) Deceased Donor Kidney Transplant Waitlist

Module 3



Updated: 12/2020

The U.S. Donor Gap



Data obtained from U.S. Department of Health & Human Services: <https://www.organdonor.gov/statistics-stories/statistics/data.html>



Potential Deceased Donor

- Brain dead or non-heart beating
- No known transmittable cancer
- Screened for transmittable diseases (e.g., HIV, Hepatitis)
- Good kidney function

Thoroughly screened, but not risk free



Start Date

- Waiting list start date is the day you started chronic dialysis.
- **For those candidates who have not started dialysis,** your start date will be the same as your listing date (GFR must be 20 mL/minute or less to qualify for point accumulation).



Life Expectancy Matching for the Top 20% of Kidneys

Kidney Donor Profile Index (KDPI)

- Age
- Height / weight
- Ethnicity / race
- History of high blood pressure
- Cause of death
- Serum creatinine
- Donation after cardiac death (DCD)
- Hepatitis C status

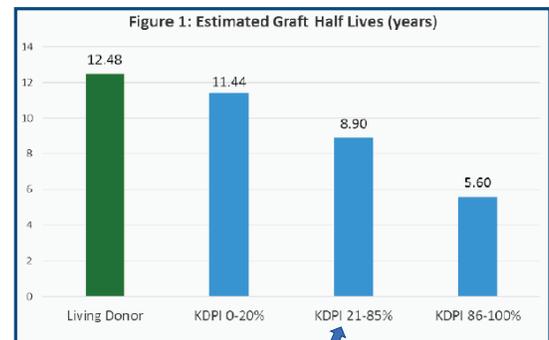
Estimated Post-Transplant Survival (EPTS)

- Age
- Diabetic status
- Time on dialysis
- Previous transplant

The lower the number, the longer the life expectancy



How Long Will the New Kidney Last?



65% of all deceased donor kidneys are between 21% and 85%

Data obtained from U.S. Department of Health & Human Services: <https://epts.transplant.hrsa.gov/resources/guidance/kidney-donor-profile-index-kdpi-guide-for-clinicians/>



UNOS Options

- Multiple listing
 - Dual listing within the VA or
 - Patients can be listed at a VA and in the private sector with the MISSION Act
- Transfer of pre-dialysis waiting time from another transplant center
- Special donor types
 - KDPI > 85%
 - Identified Risk Criteria
 - Hepatitis C
 - En Bloc
 - A2 into B
 - Dual Kidney
- **Living donor**



KDPI > 85 %

- UNOS category of donor
- **Must sign consent**
 - If signed consent, will be eligible for standard kidneys and KDPI > 85%.
- Anticipate that these kidneys will have a shorter functioning graft/life span
- All kidneys biopsied before accepting

This allows shorter waiting time for those candidates who are more likely to immediately benefit from a transplant rather than remain on dialysis!



Identified Risk Criteria

- Risk criteria present for acute transmission of hepatitis B, C, and HIV
- Dialysis patients are considered at a higher risk for the hepatitis B virus
- Infection transmission risk is very low*
- Newer testing methods have reduced risk even further
- Patient and graft survival are the same as the standard donor

➤ [*https://www.cdc.gov/mmwr/volumes/69/rr/rr6904a1.htm#T1_down](https://www.cdc.gov/mmwr/volumes/69/rr/rr6904a1.htm#T1_down)



Hepatitis C Positive Organs

- These donors have been exposed to Hepatitis C and may or may not have cleared the virus
- If the donor had not cleared the virus, you will receive medication after the transplant to cure the Hepatitis C virus
- Periodic testing for the virus after transplant
- Requires written consent



Where Are You On The List?

**We wish we could tell you...
but every list is different**

Kidney allocation is based on several factors including, but not limited to:

- Years on dialysis
- How well you genetically match the donors
- Anticipated life of the donated kidney (KDPI)
- Blood type
- Willingness to accept organs with risk criteria or HCV positive kidneys
- Sensitization (HLA antibodies)



Life On The Waiting List

- Blood draws every 28 days (**you are responsible to track these**) or you may miss a kidney offer
- Periodic updates to confirm you are still a candidate for transplant
- Temporary “Hold” for medical or social concerns (Status 7)
 - You continue to accrue waiting time
 - May impact other patients if you don’t let us know
 - Communicating with us is your responsibility! **Let us know if it’s time to reactivate you.**



The Kidney Offer Call!



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Notify Us!

- Inform our coordinator for **any** of the following:
 - Contact phone number or address changes
 - Changes to your support person
 - Antibiotics
 - Hospital admissions
 - Blood Transfusions (prior to or immediately after)
 - Kidney removal
 - Other medical concerns or medical testing at **non-VA facilities**

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Self Review: True or False

- Question 1: The Portland VA will remind me to send in a blood sample every 28 days: **True or False**
- Question 2: The more special donor types I am willing to accept, the sooner I may get an offer: **True or False**
- Question 3: It is unknown how long I will have to wait for a kidney offer: **True or False**

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Self Review: True or False

- Question 1: The Portland VA will remind me to send in a blood sample every 28 days. **False, this is your responsibility.**
- Question 2: The more special donor types I am willing to accept, the sooner I may get an offer. **True**
- Question 3: It is unknown how long I will have to wait for a kidney offer. **True**

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Up Next:

Kidney Transplant Family Education Class

Living Donor
Module 4

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Kidney Transplant Family Education Class

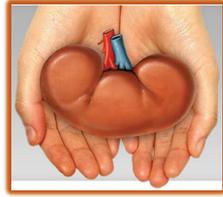
Living Donor
Module 4

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Updated: 12/16/2020

Living Donor Medical Criteria

- Age 21-70
- No high blood pressure or blood pressure medications
- Low surgical risk
- No diabetes
- BMI < 32 (Height to weight ratio)
- No transmittable diseases



Living Donor Social Criteria

Separate Donor Coordinator/Advocate

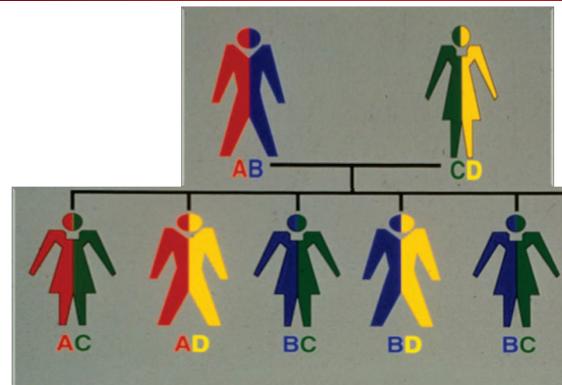
- Must be a volunteer
 - It is a **federal crime** to buy or sell organs in the United States
 - Donors cannot be offered anything of monetary value (job, raise in pay, money, cars, food, housing, etc.)
- Donors may “**Opt-Out**” of process at any time
- Needs to be an informed decision
- Adequate support / finances
- Donor and recipient must be comfortable with the process
- Realistic expectations

Starting the Living Donor Evaluation

Have the **Living Donor Candidate** contact the Independent Living Donor Advocate (ILDA) / Living Donor Nurse Coordinator

(503) 721-7860

Finding a Donor



Tissue Matching

- It's nice to share antigens (protein markers) in common, but not necessary
- A 0/6 match living donor transplant does better than a 6/6 match deceased donor transplant

Long Term Risks of Donation

- Decrease in renal function of 25%-35%
- Slight increase in blood pressure over time
- No “spare” kidney
- No increased risk of medical renal disease
 - *Avoid kidney toxic drugs for life

Life-long commitment to healthy lifestyle

Donor Surgery – Possible Options

Open Nephrectomy

- 3-4 hour surgical time
- 6-8 inch incision
- About a 3-1/2 day hospital stay
- Desk job – ~3 weeks
- Manual job – 12 weeks

Laposcopic Nephrectomy

- 4-6 hour surgical time
- One 4-inch + two 1-inch incisions
- About a 3 day hospital stay
- Desk job – ~3 weeks
- Manual job – 6 weeks



Open Nephrectomy Scar



Laposcopic Nephrectomy Scar



Self Review: True or False

- Question 1: It is ok to give money or gifts to my living donor/or their family: **True or False**
- Question 2: A potential donor can change their mind about donation at any time for any reason: **True or False**
- Question 3: My living donor has to be related to me: **True or False**



Self Review: True or False

- Question 1: It is ok to give money or gifts to my living donor/or their family: **False, it is a federal crime to buy or sell organs. Offering money or a gift in exchange for kidney donation is prohibited.**
- Question 2: A potential donor can change their mind about donation at any time for any reason: **True**
- Question 3: My living donor must be related to me: **False, a kidney from a relative may last longer because of tissue matching but any healthy person can donate to you.**



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Up Next:

Kidney Transplant Family Education Class

Antirejection medications
Module 5

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Kidney Transplant Family Education Class

Antirejection Medications Module 5



Updated: 12/16/2020

Side Effects

- All drugs have side effects
- Some are more common
- May improve as doses decrease or body gets used to the medicine
- Transplant team may be able to adjust medications to decrease symptoms



Immunosuppression Rules

- Immunosuppression is life-long
- 3 different types of immunosuppression are needed
- Doses often decrease over time
- **Do not self-adjust medications**
- Always discuss medication issues with your transplant team



Mediset



Post-Transplant Risks

- Cancer
- Heart disease
- Infections
- Diabetes



Prednisone

- Steroid that tapers over time
- Common side effects
 - Increased blood sugars (diabetes)
 - Trouble sleeping
 - Weight gain
 - Weakening of bones (osteoporosis)



Tacrolimus

- Requires lab draws (will decrease in frequency)
- Take on 12-hr schedule (8:30am & 8:30pm)
- Lab draw is 12-hr trough
 - Get blood drawn between 8am & 9am
- Do not take morning dose until after blood is drawn



Mycophenolate

- 2 forms: Cellcept® or Myfortic®
- Take with food to decrease stomach side effects
- Labs will monitor for decreased blood counts



Preventive Medications

- Immunosuppressants decrease immune system which leads to higher risk of infections
- Preventive medications
 - Anti-bacterial
 - Anti-viral
 - Anti-fungal



Medication Questions After Transplant

Transplant team will always be available to answer medication questions



Self Review: True or False

- Question 1: Immunosuppression medication and anti-rejection medications are the same thing: **True or False**
- Question 2: There is a risk that I may develop diabetes after transplant. This is a side effect of the antirejection medication: **True or False**
- Question 3: After a few years, I will no longer require antirejection medication: **True or False**



Self Review: True or False

- Question 1: Immunosuppression medication and anti-rejection medications are the same thing: **True**
- Question 2: There is a risk that I may develop diabetes after transplant. This is a side effect of the antirejection medication: **True**
- Question 3: After a few years, I will no longer require antirejection medication: **False, you will require life-long antirejection medication**





Up Next:

Kidney Transplant Family Education Class

Transplant Surgery Module 6

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Kidney Transplant Family Education Class

Surgery and Beyond Module 6

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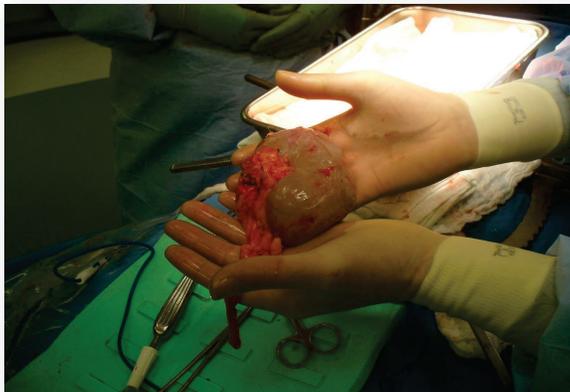
Surgical Risks

All surgeries have risks!

- Anesthesia reaction
- Urine leak
- Urine blockage
- Fluid collection
- Bleeding
- Blood clot
- Infection



Less than 5% re-operation rate in the first month



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Recipient Hospital Course

- 2-4 hours in the operating room
- Incision about 6 inches
- Usual post-op activity
- Foley catheter, wound drains, central line, arm IV
- Dialysis, if needed
- About a 3-5 day stay
- Education, education, education for both the Veteran and the support person

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Delayed Graft Function

- 33-40% of deceased donor transplants are “sleepy”
- Can last days to weeks to months
- May require temporary dialysis
- Rare with living donor transplant

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Acute Rejection

- Usually seen within the first three months
 - Often no symptoms
 - Self monitoring is essential (labs, weight, BP, temperature)
- Treatment available
 - May require admission to hospital, biopsy, and IV medications
 - 95% reversible



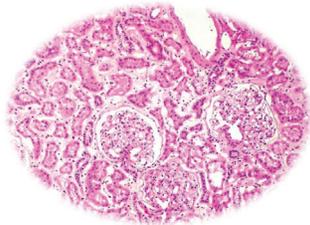
Chronic Rejection

- Usually seen after one year
- Treatment available to stall process
- Not reversible
- Eventual loss of transplant
 - Return to dialysis vs. repeat transplant?



Biopsy

- As needed if concerned about rejection



Why Do Kidney Transplants Fail?

- Return of original disease
- Noncompliance with medical treatment
- Need to decrease or stop anti-rejection medications because of other health issues
- Chronic rejection/changes over time
- Rarely, surgical complications



Your Responsibilities

- Follow lab/clinic schedules
- Monitor own labs
- Monitor temperature/BP/weight
- Take medications exactly as prescribed
- Be a proactive partner in care



Referring Back to General Nephrology

- At about three months if all is well
- We will continue to monitor kidney function
- We will act as consultants
- Regular visits with transplant team



Lifestyle After Transplant Cardiac (Heart)

- Heart healthy diet
- Exercise
- Blood pressure and cholesterol control
- No smoking
- Healthy weight
- Testing as indicated *



* As recommended by the American Heart Association and the American College of Cardiology Foundation



Lifestyle After Transplant Cancer

Routine Screening *

- Pap/Mammogram
- Breast self-exam
- Colonoscopy
- Prostate screening

Skin Care

- Sunscreen
- Regular skin checks
- Stay out of the sun
- Dermatology



* As recommended by the American Cancer Society



Lifestyle After Transplant Infection

Use common sense!

- Wash your hands
- Take food precautions
- Don't share food/utensils
- Use gloves when gardening
- Avoid people with contagious diseases
- Pet considerations
- Dental follow-up



Self Review: True or False

- Question 1: I may require dialysis after my transplant. **True or False**
- Question 2: Taking my medication **exactly** as prescribed is important to avoid rejection. **True or False**
- Question 3: I should expect to have frequent biopsies. **True or False.**



Self Review: True or False

- Question 1: I may require dialysis after my transplant. **True**, we expect that this would be temporary if you need it.
- Question 2: Taking my medication **exactly** as prescribed is important to avoid rejection. **True**, this is one of the most important things you can do to make your kidney last longer.
- Question 3: I should expect to have frequent biopsies. **False**, biopsies are only required if there are concerns about your kidney.



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Up Next:

Kidney Transplant Family Education Class

Transplant Surgery
Module 7

Portland
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Kidney Transplant Family Education Class

Social Support & Preparation Module 7



Updated: 12/17/2020

Support Person

- Why do you need a support?
 - Partner in Care – Your Caregiver
 - Lifting Restrictions
- Who makes a good support?
 - Someone who is invested in your success! Usually, a family member or close friend.
 - No paid support
 - Shared room with 2 twin beds



Support Person Availability

- If your support person is unavailable at the time of kidney offer you will not be eligible for a transplant
- Consider identifying a back-up support plan if your first support might be unavailable
- Back-up support will need to be screened by the transplant social worker
- Notify the transplant team if your support person is unavailable for any reason



Tips for Planning Ahead

- **Equipment to bring with you:** thermometer, CPAP, and BP cuff
- Plan finances for home and at Portland VA
 - Bill autopay
 - Separate savings plan for Portland expenses
- Housing Plans for stay at the VA
- Driving restrictions/transportation
- Distance from the VA
- Plans for referring/home VA to get you to Portland VA



What Expenses Does the VA Cover?

- Transportation from airport to lodging on arrival
- Transportation from lodging to the airport at departure
- Shuttle service between the lodging and the hospital from Monday-Friday
- Lodging at the Transplant Lodge, Fisher House, or a contracted hotel
- Medical care
- You may locate the travel reimbursement form by visiting: <https://www.va.gov/vaforms/medical/pdf/vha-10-3542-fill.pdf>



What Expenses Are Not Covered By the VA?

- Be prepared to utilize taxi/rideshare apps or public transit
- Cost of food/groceries
- Personal expenses
- No financial compensation for support



Sorry, No Pets Allowed

- Have a plan in place for your pet's care while you are in Portland
- No pets, including emotional support or service animals
- Lodging will not be provided for pets
- The VA will not pay for boarding your pet



Financial Implications

Finances could change!

- Service Connection
 - Contact your Veterans Service Officer (VSO) at your home VA for more information
- Medicare/Disability
 - Contact your local social security office in your home state for more information
- For questions related to co-pays, waivers, coding and billing:
 - Call the CPAC at (503) 273-5217
- For questions related to ambulance rides or transportation bills:
 - Call Veterans Transportation Services at (503) 220-8262 x55101



Self Review: True or False

- Question 1: Social support is required for transplant:
True or False
- Question 2: I will need to arrange my own lodging:
True or False
- Question 3: I can be reimbursed for transportation between the airport and the hospital or Lodge:
True or False



Self Review: True or False

- Question 1: Social support is required for transplant:
True
- Question 2: I will need to arrange my own lodging:
False, Lodging will be arranged and provided by the VA unless you choose to make your own arrangements. Lodging costs not arranged by the VA will not be reimbursed.
- Question 3: I can be reimbursed for transportation between the airport and the hospital or Lodge: **True**



Congratulations!

