



# **Peer Mentorship Training Program Discussing Transplant as an Option**

Revised July 2018

# Welcome!





# IPRO End Stage Renal Disease (ESRD) Network

## Mission

- To promote healthcare for all ESRD patients that is safe, effective, efficient, patient-centered, timely and equitable.

## Role and Responsibilities

- Improve quality of care for individuals with ESRD.
- Promote patient engagement and patient experience of care.
- Process grievances from patients, or their representatives by conducting confidential investigations.
- Support emergency preparedness and disaster response.
- Provide education and resources to individuals with ESRD, dialysis facilities and transplant centers.



## What is Peer Mentoring and what is your role?

- Peer mentoring is a relationship between a person who has had experience dealing with a topic, such as Transplant, and a person who is new to that experience. The peer mentor relationship is used to help the less experienced person (mentee) achieve his or her goals by receiving assistance and guidance from the more experienced person.
- As a peer mentor you will:
  - Share your personal experiences as a kidney patient.
  - Offer educational resources and tools.
  - Encourage your mentee to be engaged and active in his or her care decisions.
  - Help your mentee identify and access additional support and resources.

# Consider these Qualities that can help you become an Effective Mentor



- **Ability and willingness to communicate to mentee what you know**
  - As a mentor you are seen as someone who is knowledgeable about kidney care choices. Stay alert for new topics that may impact you or your role as a peer mentor
- **Being prepared**
  - Being a mentor means making an important commitment to your mentee; be prepared for each mentoring session to provide useful, guidance while ensuring that your mentee takes the lead and makes his or her own healthcare decisions .
- **Being approachable and having the ability to listen**
  - Your mentee must feel comfortable approaching you. As the mentor you should be ready to listen and provide guidance to mentee. Keep mentee goals in mind by being trustworthy, modeling positive behavior and offering support.

**All of these qualities should be the compass that guides all your actions as a mentor.**

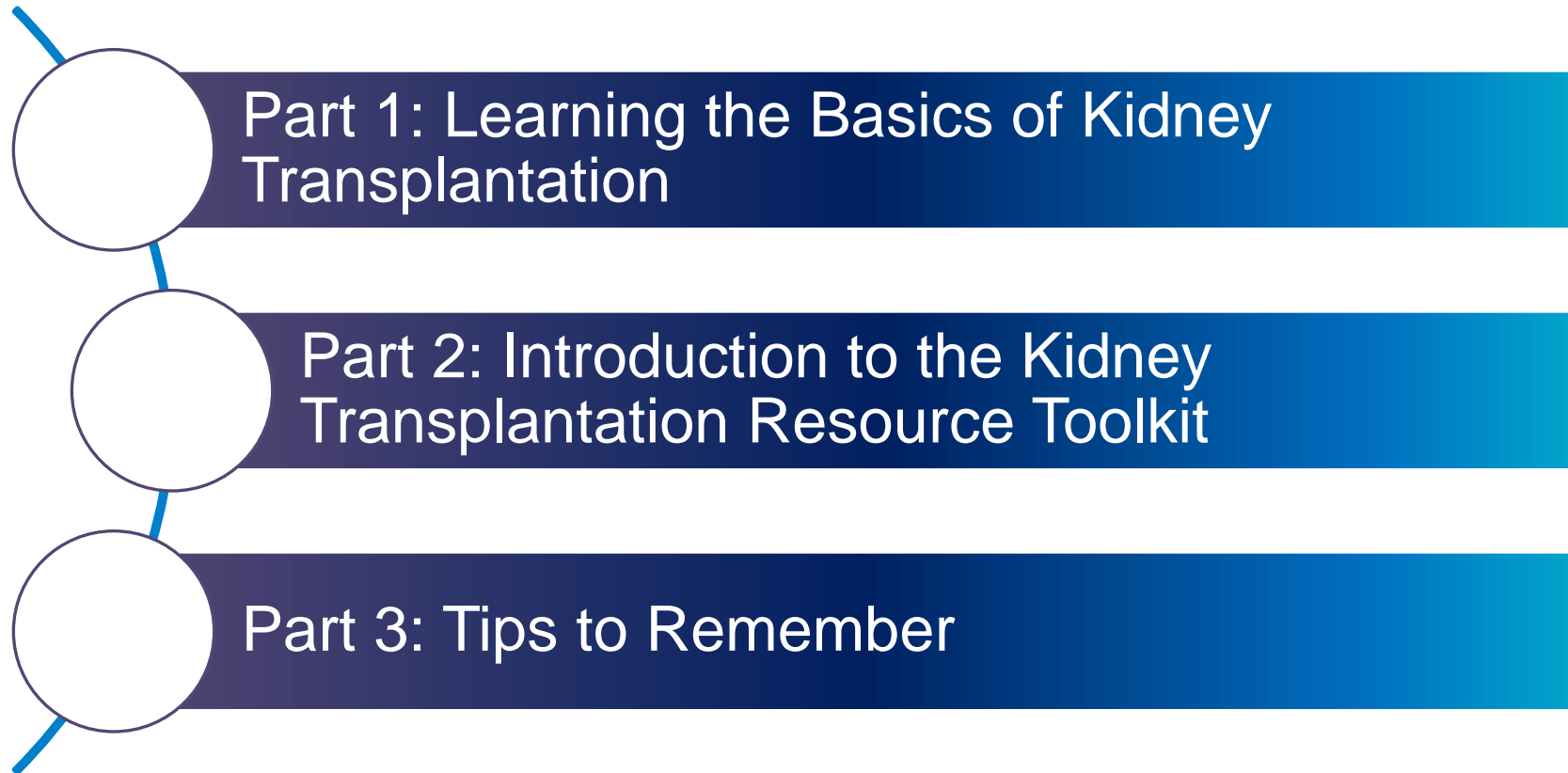


## What will you gain from being a Peer Mentor?

- **Improve communication and personal skills**
- **Develop leadership and management qualities**
- **Strengthen your own skills and knowledge**
- **Benefit from a sense of fulfilment and personal growth**
- **Gain recognition for your skills and experience**
- **Support your facility in meeting their quality improvement goals**
- **Partnership with the ESRD Network**
- **Opportunity to share you feedback at a national level**

**The chance to make a POSITIVE impact on someone's life  
is a priceless experience.**

# What will be covered in this Module?



**This module will help you guide your mentee to get the answer to the following questions:**

- Is transplant an option for me?
- Would a kidney transplant be a cure for me?
- Where or from whom can I get a kidney?
- How long will the process take?





# **Part 1: Learning the Basics of Kidney Transplantation**



# What is a kidney transplant?

**A surgery in which a person whose kidneys have failed receives a new kidney (first-time or replacement).**

- The new kidney takes over the work of cleaning the blood.
- The new kidney comes from another person.
- Only one kidney is transplanted.
- The original kidneys are generally not removed.

## Important things to keep in mind

- Transplant is not an option for everyone.
- Your mentee will be evaluated for a transplant by the transplant center.



# Why is transplant an important treatment choice for consideration?

A kidney transplant is the most effective treatment and the only treatment that will work 24 hours a day.

## Remember:

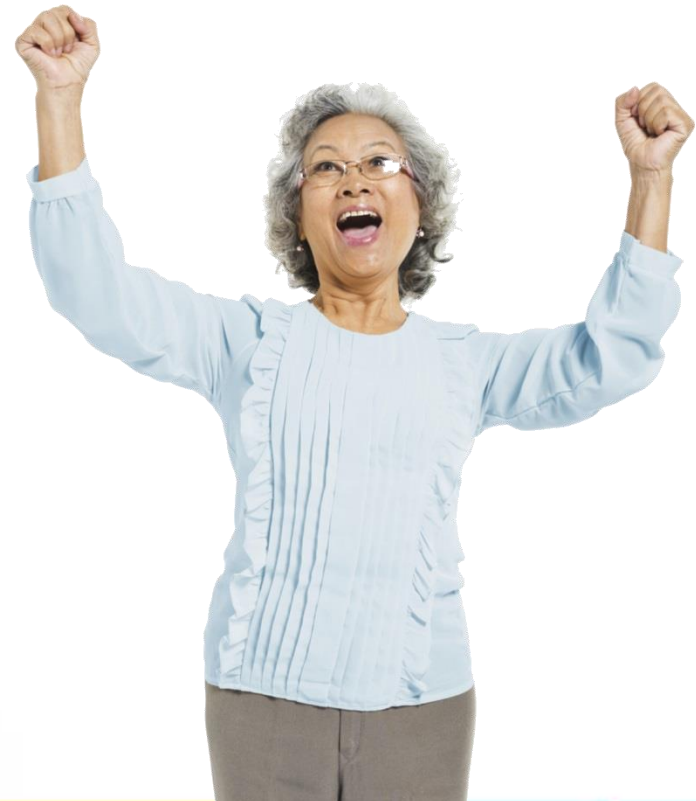
- Kidney transplant is one of several treatment options.
- It doesn't permanently restore kidney function or cure kidney disease.
- The average life span for a donated kidney is 10 to 15 years.
- You can be re-listed for another transplant



# What are some of the benefits of kidney transplant?

## Improved health and quality of life.

- Greater freedom (no dialysis treatments)
- Increased energy levels
- Fewer diet restrictions



## What are some additional considerations about kidney transplant?

- Surgery recovery
- Possible kidney rejection
- Anti-rejection medication
  - Side effects
  - Needed daily to maintain transplanted kidney
- Additional medical expenses

# Types of kidney donors

There are two types of donors:

Someone who has passed away, but either previously agreed (or their next of kin agrees to) donate their healthy organs.

Non-Living Donor

Living Donor

Could be anyone who is a match to you and wants to donate.

Both types of Kidney Transplant will require an evaluation by the Transplant Center



## The Process:

# Non-living kidney donor transplant

### Waiting for a kidney from a non-living kidney donor:

- Anyone who chooses transplant from a non-living kidney donor will need to go on a waiting list.
- The national waiting list follows strict guidelines to maintain a fair and equitable distribution of organ donation.

Since December 2014, the National Kidney Allocation System changed to prioritize patients who have been on dialysis longer.



# Organ Transplant Waiting List

## The Match

**Time on the waiting list can depend on several factors that contribute to the match, including:**

- Geographical proximity
- The recipient blood type
- Age
- Weight and height
- Health history
- Support system
- Length of time on dialysis
- Length of time being active on the transplant waiting list

## The Process:

### Living kidney donor transplant

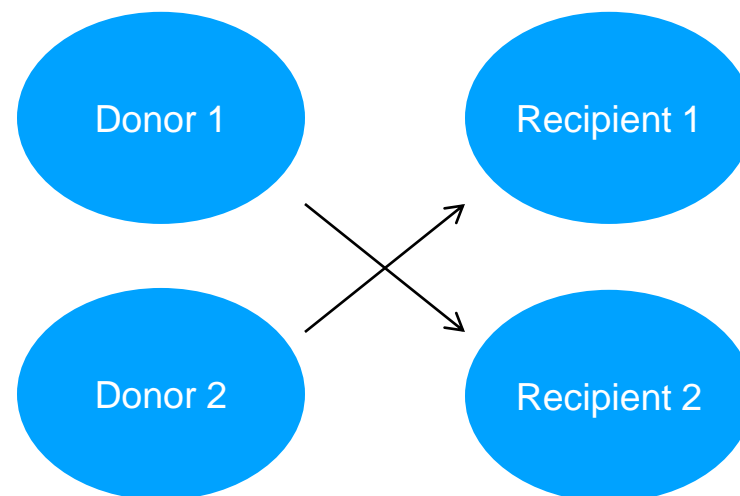
#### Waiting for a transplant from a **living** kidney donor:

- Waiting time is based on the time it takes to evaluate the mentee's living donor(s).
- Living donors are fully evaluated to:
  - Make sure that donating a kidney is safer for them.
  - Test that they are a good match to recipient.
- The waiting time for a transplant from a living kidney donor is usually shorter than the waiting time for a transplant from a non-living kidney donor.

# Waiting for a living kidney donor transplant

## Transplant from a **living** kidney donor:

- If the person willing to donate your mentee is not a direct match:
  - There are multiple paired kidney exchange programs, also known as “kidney swap”.



# Kidney transplant considerations

- **Some people are not interested in transplant as an option**
- **Reasons are varied, but some include**
  - Fear
  - Lack of information
  - Misinformation
  - Religion or other believes
- **Remember to provide information with sensitivity and always **respect** your mentee's believes.**

## Discussing transplant as an option

**Everyone is different. What is right for one person, is not always right for another.  
Transplant is not an option for everyone.**

**Remember to always speak with your mentee about transplant as a potential choice.**

# **Part 2: Introduction to the Kidney Transplantation Resource Toolkit**



# What materials are in our toolkit?

**“Is a Kidney  
Transplant Right  
for Me? Your  
Guide to the  
Transplant  
Process”  
Manual**

**““Your Life, Your Choice: Kidney  
Recipient/Donor Patient Story” Booklet**

**“Get the Facts: Kidney Transplantation” Brochure**

## Tool #1

# “Get the Facts: Kidney Transplantation” Brochure

**Basic factual information to know  
when considering transplant as an option.**





## Tool #1: What's covered?

### “Get the Facts: Kidney Transplantation” Brochure Topics:

- What is a kidney transplant?
- What are the different types of kidney donors?
- What do I need to know about getting a kidney transplant?
- How will my life change after I get a transplant?
- How will I pay for my kidney transplant?
- What are some outcomes of a kidney transplant?
- What are some considerations about having a kidney transplant?

# Tool #1: Assess your mentee's needs

## Ask open-ended questions

- What do you know about transplantation?
- What type of information have you received?
- What other information do





# Tool #1: Support your mentee's needs

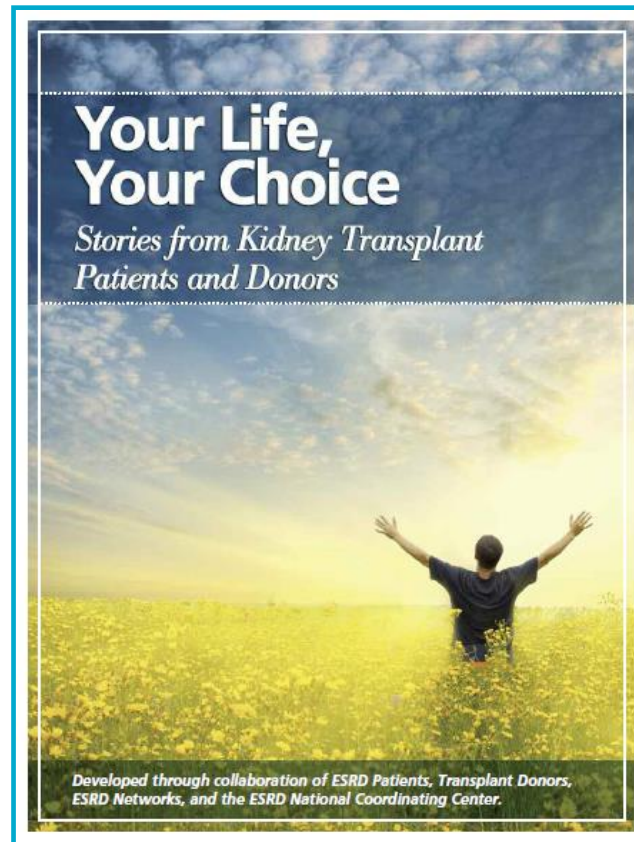
## Your mentee's understanding of transplant:

- **Mentee: Doesn't have enough information**
  - ✓ **You:** Share and review "Get the Facts" brochure.
- **Mentee: Asks for more clinical information**
  - ✓ **You:** Connect mentee to healthcare team for questions.
- **Mentee: Indicates that he or she needs more time to think it over.**
  - ✓ **You:** Provide "Get the Facts" brochure and ask if you can be of any further assistance in answering any questions and provide support.
  - ✓ Refer your mentee to the healthcare team for help when he or she is ready to take the next step.

# Tool #2

## “Your Life, Your Choices”

Stories of kidney transplant recipients and donors,  
told in their own words.





## Tool #2: “Your Life, Your Choices”

### This tool can help your mentee:

- Better understand to navigate the transplant experience, based on the perspective of individuals who have already gone through it.
- Learn more about the transplant process and think about their situation differently after hearing from other peers.
- Provides information on how other patients overcame concerns or barriers related to transplant.

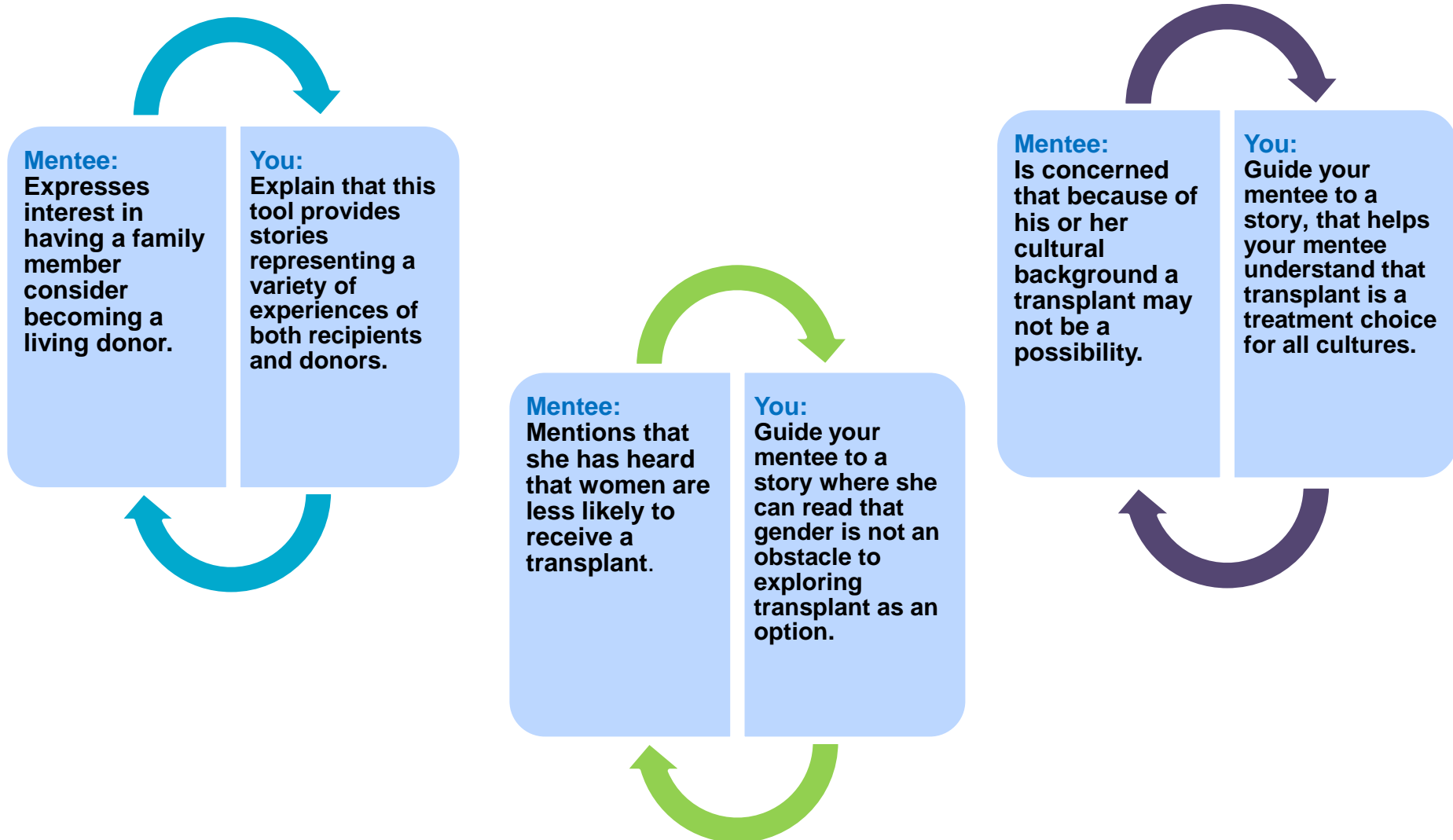
## Tool #2: What's covered?

**Real-life stories, as told by recipients and donors from different parts of the country.**

- Designed to motivate and empower ESRD patient to explore all treatments modality choices, including kidney transplant.
- The stories were developed to help address what patients perceive as barriers to receiving a kidney transplant.



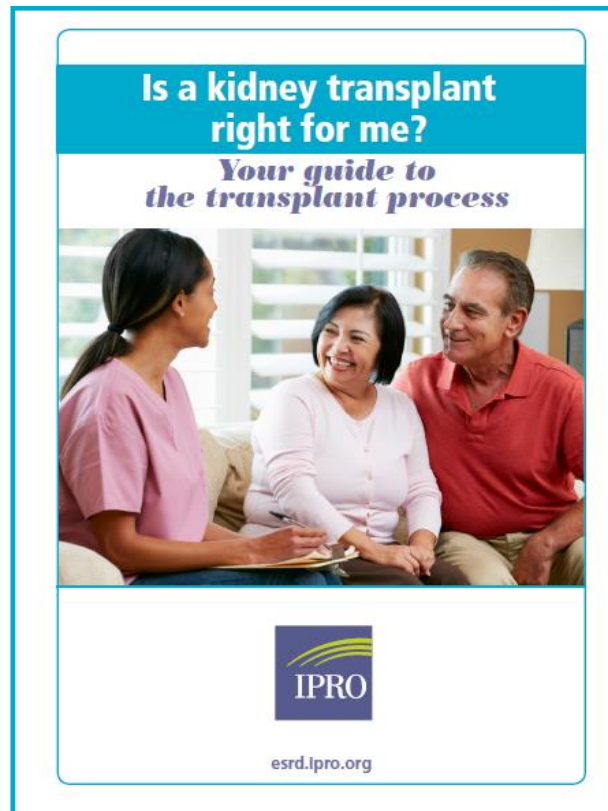
## Tool #2: Support your mentee's needs



## Tool #3

# “Is a kidney transplant right for me?” Manual

A detailed overview of the steps leading to a transplant and care after surgery.







# Tool #3: What's covered?

## “Is a kidney transplant right for me?” Manual Topics:

- **Introduction**
  - Overview of transplant as an option.
- **What is a transplant center?**
  - The new Kidney Allocation System.
  - Types of kidney donors.
- **What is the waiting list?**
  - The process that must be followed if your mentee has to wait for a non-living donor transplant.
  - The multiple waitlist option.
- **What is the surgery like?**
  - Surgery time and procedure.

## Tool #3: What's covered?

- **What happens after the surgery?**
  - Immediately after-surgery care.
  - Ongoing and long-term healthcare needs require to keep a transplant.
- **How much does a kidney transplant cost?**
  - Which surgery and medication costs are covered by Medicare?
  - Explanation of long-term medication costs.
- **Who are the members of the transplant team?**
  - Every member of the healthcare team that will work with our mentee as he or she considers transplant.
- **More questions?**
  - Questions to help your mentee get needed information from his or her healthcare team.

# Tool #3: Assessing and supporting your mentee's needs

- **Mentee:** has questions about how to register for the kidney transplant waiting list.
  - ✓ **You:** Refer your mentee to the “What is the Waiting List” section (page 5) of the tool.

## There are two types of donors: living donors and non-living donors.

A living donor could be anyone who is a match to you and wants to donate. A non-living donor is someone who has passed away but had previously agreed to donate a healthy kidney after their death. There is a waiting list for kidneys from non-living donors. There are more people in need of kidneys than there are kidneys available.

A donor kidney must meet certain standards. The donor kidney also must match the blood and tissue types of the person who is to receive the kidney. Patients and potential live donors have to undergo several medical tests to find out if the kidney will be a good match. If a patient is going to get a kidney from someone who is deceased, he or she will be placed on a waiting list. Their blood and tissue types will be listed in their file.

## What is the Waiting List?

If you need a deceased donor kidney, you will be placed on a waiting list until a kidney is available. Waiting time can depend on several factors. These include your age, how long you have been on dialysis, your health history, and how long you have been on the waiting list. When a donor organ becomes available, the person who is the best match will receive the transplant.

The transplant must take place very soon after the kidney becomes available. A member of the transplant staff usually calls the person who needs a kidney. He or she must go immediately to the hospital transplant center. The transplant team can tell you more about how the waiting list works.

Some people may want to place their name on more than one transplant list. For more information visit the United Network for Organ Sharing (UNOS) website at [www.unos.org](http://www.unos.org).



# Tool #3: Assessing and supporting your mentee's needs

## What is the Surgery Like?

When a donor kidney is available, doctors carry out more tests to confirm that it will be accepted by the recipient. Once they decide it is a good match, the patient will be taken to surgery.

The surgery takes approximately two to four hours and is done under general anesthesia. The donor kidney is placed in the lower abdomen. It is attached to blood vessels and the tube that drains urine into the bladder. Most of the time the old kidneys are not taken out unless they are infected or too large.

## What Happens After the Surgery?

After surgery, you will be given medications that help prevent rejection of the donor kidney. Your transplant team will check to make sure the new kidney is working. Your new kidney may start to work and produce urine immediately. If it doesn't, you may have to go on dialysis for a while until your new kidney begins to work.

After you recover from the surgery you will be able to go home. Your transplant team will follow you closely. You will take medications to prevent rejection as long as your transplant is working. Your medications will be adjusted as your kidney function changes.

It is very important to visit the transplant team for regular checkups. This allows any problems to be found early. Rejection of the kidney is always possible.



The medications you must take after the transplant will weaken your immune system. This can lead to infections. You should ask a member of your transplant team about which medications you will need to take after the transplant. Make sure you ask about any side effects.

Over time, these medications may also increase the risk of cancer. People who take them should never sunbathe or use tanning beds because of the increased risk of skin cancer.

Your diet will change, depending on how your new kidney is working. You may be able to eat different foods and drink more fluid. Your dietitian will help you understand your new diet.

You will have to watch your weight and blood pressure. Anti-rejection medications may cause you to gain weight and/or have higher blood sugar. Avoiding salty foods will help keep your blood pressure at a healthy level and will help avoid swelling. If you have diabetes, continue to follow your diabetic diet. Other than follow-up care, a person who has had a kidney transplant is able to live a fairly normal life.

- **Mentee:** is concerned about the recovery process after transplant surgery.
- ✓ **You:** Review with your mentee the “What Happens After the Surgery” section (page 6) of the tool.

## Tool #3: Assessing and supporting your mentee's needs

- **Mentee:** Is worried about insurance coverage for kidney transplant.
- ✓ **You:** Guide your mentee to the “How Much Does a Kidney Transplant Cost” section (page 7) of the tool.

### How Much Does a Kidney Transplant Cost?

Having a kidney transplant is expensive. You can work with the transplant center team to figure out what you might have to pay. Ask them to help you make a financial plan for this. Medicare and most private insurances will usually cover the costs. Medicare will cover 100% of a living donor's hospital costs. It will also cover any pre-transplant work-ups.

Patients need to know the monthly cost of the medications that keep their bodies from rejecting the transplant. With Medicare and a private insurance, there will be some out-of-pocket expenses. Ask the transplant social worker to tell you about any additional costs you can expect.

If a person has Medicare coverage only because of kidney failure, Medicare payments will stop three years after the transplant. The patient will need to find other health insurance before Medicare coverage ends.

Many of the companies that make the anti-rejection medications will work with patients, their doctors and pharmacists to help pay for medications. The transplant team social worker can help find local resources and programs to assist patients. There are also many generic drugs that might work. Each patient will need to discuss this with the transplant team.

Some transplant centers make sure that kidney recipients have a plan in place to pay for medications. If a patient cannot pay for the medications and stops taking them, his or her body will reject the kidney. The patient will then need to go back on dialysis.



# **Part 3:**

# **Tips for success**



# Tips for supporting your mentee

Once you have completed reviewing the Kidney Transplantation Toolkit with your mentee, it is up to your mentee to take the necessary actions toward a transplant referral.

## Remember:

- Encourage your mentee to talk to a member of his or her care team about getting a transplant referral.
- Your mentee may not want to proceed at this point, and that is OK! You have succeeded in your role as a mentor by providing him or her with important information.

# Tips for supporting your mentee

**Check in with your mentee as often as you can to provide encouragement.**

## **If your mentee:**

- Runs into any obstacles...
  - ✓ Help by connecting him or her with the healthcare team.
- Has questions along the way...
  - ✓ Reinforce information from the toolkit.
- Learns that transplant is not an option...
  - ✓ Provide support as he or she deals with this news.



## **Tips for supporting your mentee**

**Always remember there are other options for treatment that your mentee can consider.**

**The best choice is the one that is right for him or her.**



## Some important additional resources

- Your Dialysis Facility
- Your IPRO End Stage Renal Disease (ESRD) Network has several resources that can help you and your mentees [www.ipro.org](http://www.ipro.org)
- United Network for Organ Sharing [www.unos.org](http://www.unos.org)
- National Institute of Diabetes and Digestive and Kidney Disease [www.niddk.nih.gov](http://www.niddk.nih.gov)

# Next Steps





## Congratulations on completing the Discussing Transplant as an Option Module!

- Next, please complete the module “**Review Quiz**” to earn your completion certificate.
- Share your completion certificate with your facility point of contact.
- Request printed copies of the supporting resources.
- Work with your facility point of contact to identify mentees and begin sharing your experience and the resource information from this module.

**You have completed training to mentor  
your peers on the topic of Discussing  
Transplant as an Option Module!**



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