PEER MENTORSHIP TRAINING PROGRAM
ESRD National Coordinating Center (NCC)

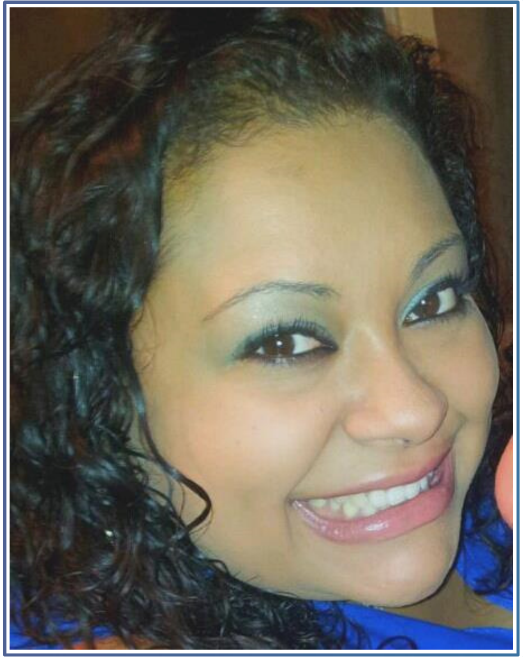
National Patient/Family Engagement
Learning and Action Network (N-PFE LAN)
Published: July 2015

Peer Mentorship Training Program

Patients Helping Patients Learn About Kidney Care Choices

ESRD NCC
NATIONAL
COORDINATING
CENTER

Meet your course instructors



Jeanine Pilgrim

Patient/Family Engagement
Project Manager

Vicky Cash

Assistant Director of
Quality Improvement

ESRD NCC
NATIONAL COORDINATING CENTER

MODULE 3A

Discussing Transplant as an Option

ESRD NCC
NATIONAL
COORDINATING
CENTER

What will be covered in this Module?

- Part 1: Learning the Basics of Kidney Transplantation
- Part 2: Introduction to the Kidney Transplantation Resource Toolkit
- Part 3: Using the Toolkit
- Part 4: Tips to Remember

ESRD NCC
NATIONAL COORDINATING CENTER

Getting started

Think back to when you were first told about your diagnosis:

- Were you overwhelmed?
- Did you feel lonely or alone?
- Was it hard to absorb things you were being told?
- Did you receive too much information in too short a time?
- Did you feel that important pieces of information not provided?

Helping your peer make important choices

A newly diagnosed kidney patient faces many important questions including:

- How should I receive treatment?
- What type of vascular access should I have?
- What can I do to prevent infections?
- Is transplant an option for me?

Many of these decisions can affect your quality of life and experience of care.

ESRD NCC
NATIONAL
COORDINATING
CENTER

Your role as a mentor

- Share your personal experiences as a new kidney patient.
- Offer educational resources and tools.
- Encourage your peer to be engaged and active in his or her care decisions.
- Help your peer get in touch with someone at his or her Network for additional support and resources.

ESRD NCC NATIONAL COORDINATING CENTER

PART 1

Learning the Basics of Kidney Transplantation

ESRD NCC
NATIONAL
COORDINATING
CENTER

What is a kidney transplant?

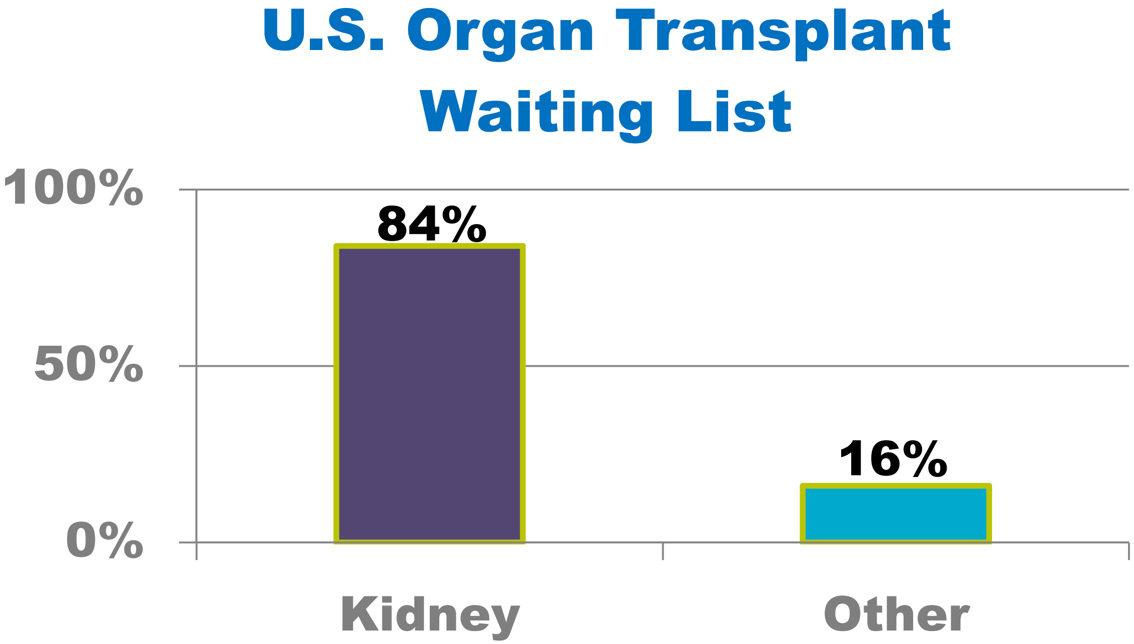
A surgery in which a person whose kidneys have failed receives a new kidney (first-time or replacement).

- The new kidney takes over the work of cleaning the blood.
- The new kidney comes from another person.
- Only one kidney is transplanted.

ESRD NCC NATIONAL COORDINATING CENTER

Organ transplant waiting list

- More than 120,000 people are currently waiting for lifesaving organ transplants in the U.S.
- Of these, more than 100,000 individuals await kidney transplants.



Types of kidney donors

There are two types of donors:

living donors and non-living donors.

Non-Living Donor

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

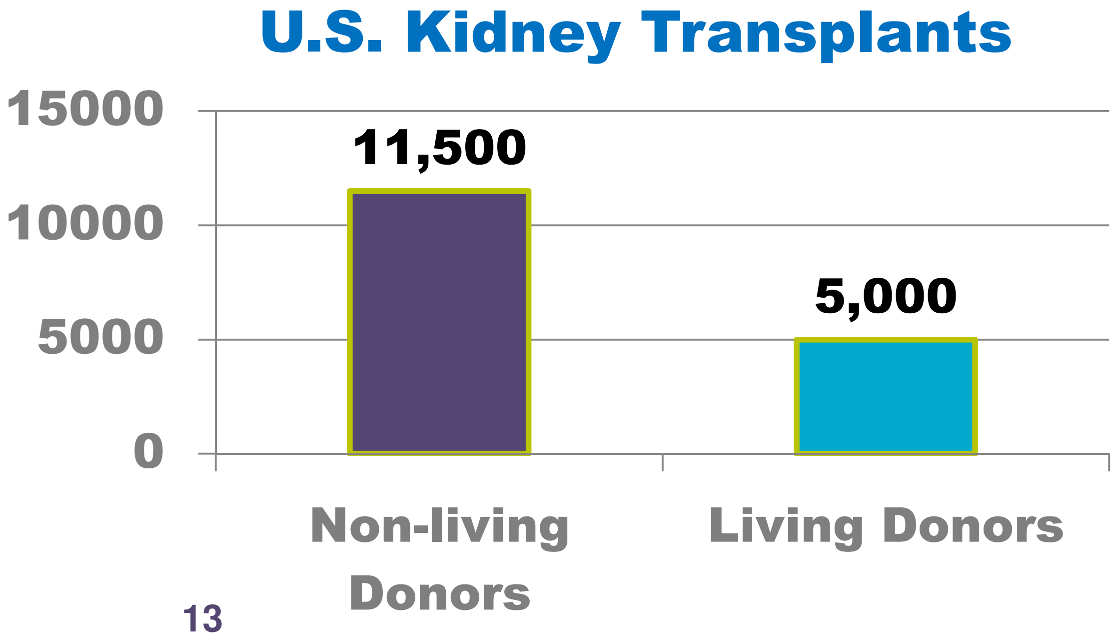
Living Donor

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

ESRD NCC
NATIONAL COORDINATING CENTER

Kidney transplant facts

- In 2014, more than 17,000 kidney transplants took place in the U.S.
- Of these, more than 11,500 came from non-living donors and more than 5,000 came from living donors.



Transplant facts

- Transplant is not an option for everyone.
- Your peer will be evaluated for a transplant by the transplant center team.
- The transplanted kidney must:
  - Meet certain standards to be used.
  - Be a match for your peer’s blood and tissue type.

Waiting for a non-living kidney donor transplant

Transplant from a non-living kidney donor:

- **Anyone who chooses transplant from a non-living kidney donor will need to go on a waiting list.**
- **Time on the waiting list can depend on several patient factors, including:**
  - The recipients blood type
  - Age
  - Health history
  - Support system
  - Length of time on dialysis
  - Length of time being active on the transplant waiting list.

Waiting for a non-living kidney donor transplant

Transplant from a non-living kidney donor:

- The national waiting list follows strict guidelines to maintain a fair and equitable distribution of organ donation.
- More than 3,000 new patients are added to the kidney waiting list each month.

Waiting for a living kidney donor transplant

Transplant from a living kidney donor:

- Waiting time is based on the time it takes to evaluate the peer's living donors.
- Living donors are fully evaluated to:
    - Make sure that donating a kidney is safe for them.
    - Test that they are a good match to the recipient.

Waiting for a living kidney donor transplant

Transplant from a living kidney donor:

- 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.
- There are multiple programs for living kidney donation that the peer should learn about to know all their options.

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 your 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.**

What are some of the positive outcomes of kidney transplant?

Improved health and quality of life.

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

What are some of the considerations of kidney transplant?

- Surgery recovery
- Possible kidney rejection and anti-rejection medication side effects
- Additional medical expenses

ESRD NCC
NATIONAL COORDINATING CENTER

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 peer about transplant as a potential choice.

PART 2

Introduction to the Kidney Transplantation Resource Toolkit

ESRD NCC
NATIONAL
COORDINATING
CENTER

What materials are in our toolkit?

"Is a
Kidney
Transplant
Right for Me?
Your Guide to the
Transplant Process"

"Your Life, Your Choice: Kidney
Recipient/Donor Patient Story"

"Get the Facts: Kidney Transplantation"

Tool #1: Transplant Fact Sheet

Types of Kidney Donors

Living Donor

- A living related donor kidney comes from a blood relative, such as a parent, brother, sister, or an adult child, and is the best transplant option.
- A living unrelated donor kidney comes from someone who is not related to the person receiving the kidney.
- The donor is evaluated by the transplant center to make sure he/she is healthy enough to donate and is offering his/her kidney willingly, without pressure from anyone.

Non-Living Donor

- A non-living donor is someone who has recently died and has donated a healthy kidney.
- Patients who do not have a living donor can be placed on the national organ transplant waiting list to receive a deceased donor kidney.

Kidney Donor Exchange

- If your kidney donor is approved for a living donation but is not a match with you, you and the donor may be able to join a living donor exchange program.

For more information: www.unos.org

For more information

ESRD NCC
NATIONAL
COORDINATING
CENTER

End Stage Renal Disease National Coordinating Center

website: www.esrdncc.org
e-mail: ncc@ncc.esrd.net
(516) 209-5253
www.facebook.com/esrd.ncc
@esrdncc

Prepared by the National Patient and Family Engagement (N-PFE) Learning and Action Network (LAN), under the ESRD NCC. The ESRD NCC gratefully acknowledges the following ESRD Networks as sources for development of the content used in this resource: FMQAI: The Florida ESRD Network 7, Network 8, Inc., and Heartland Kidney Network 12.

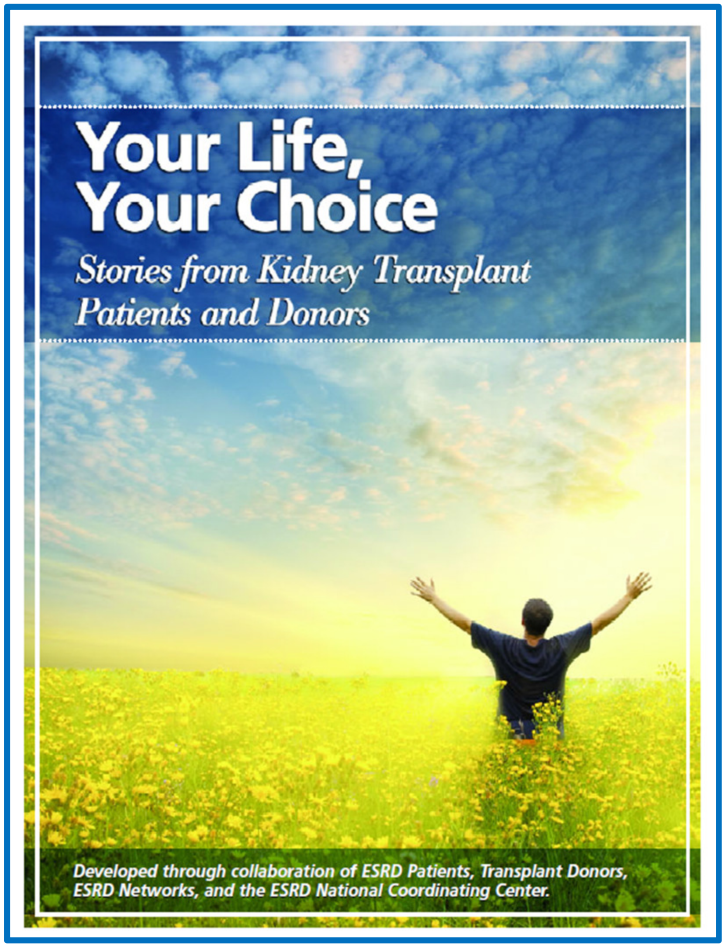
This publication was developed under Contract Number HHSM-500-2013-NW002C, titled "End Stage Renal Disease National Coordinating Center (ESRD NCC)," sponsored by the Centers for Medicare & Medicaid Services (CMS), Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy.

Get the Facts: Kidney Transplantation

Learn the facts about getting a kidney transplant and how it might affect you before you make decisions about your treatment.

ESRD NCC
NATIONAL
COORDINATING
CENTER

Tool #2: Transplant Story Booklet



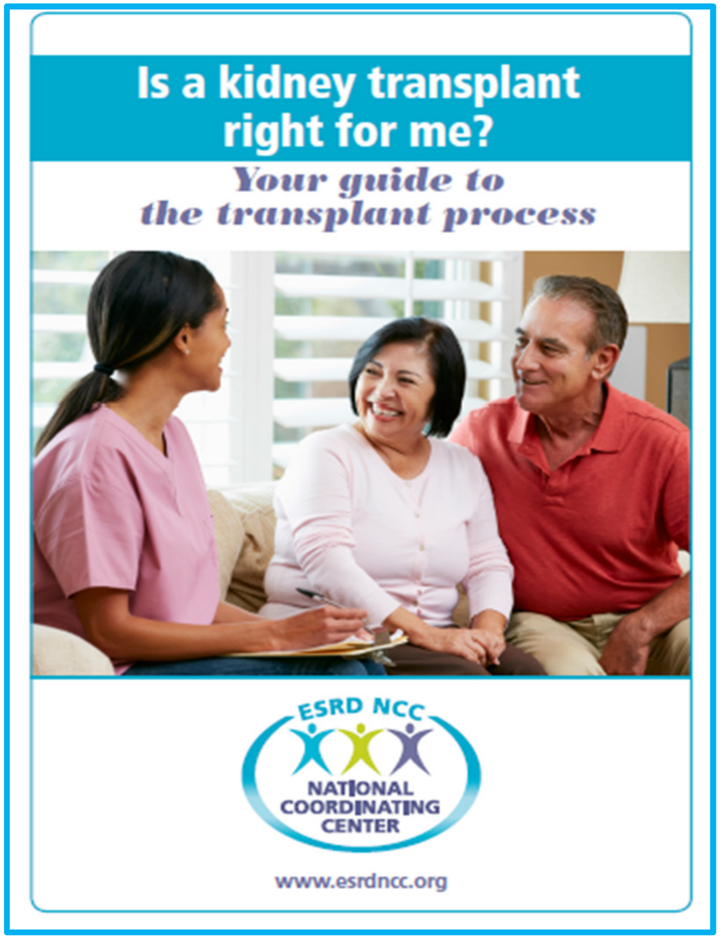
Your Life, Your Choice

Stories from Kidney Transplant Patients and Donors

Developed through collaboration of ESRD Patients, Transplant Donors, ESRD Networks, and the ESRD National Coordinating Center.

ESRD NCC
NATIONAL
COORDINATING
CENTER

Tool #3: Transplant Process Guide



Is a kidney transplant right for me?

Your guide to the transplant process

ESRD NCC
NATIONAL
COORDINATING
CENTER

www.esrdncc.org

ESRD NCC
NATIONAL
COORDINATING
CENTER

PART 3

Using the Resource Toolkit

ESRD NCC
NATIONAL
COORDINATING
CENTER

Tool #1: “Get the Facts: Kidney Transplantation”

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

Types of Kidney Donors

Living Donor

- A living related donor kidney comes from a blood relative, such as a parent, brother, sister, or an adult child, and is the best transplant option.
- A living unrelated donor kidney comes from someone who is not related to the person receiving the kidney.
- The donor is evaluated by the transplant center to make sure he/she is healthy enough to donate and is offering his/her kidney willingly, without pressure from anyone.

Non-Living Donor

- A non-living donor is someone who has recently died and has donated a healthy kidney.
- Patients who do not have a living donor can be placed on the national organ transplant waiting list to receive a deceased donor kidney.

Kidney Donor Exchange

- If your kidney donor is approved for a living donation but is not a match with you, you and the donor may be able to join a living donor exchange program.

For more information

ESRD NCC
NATIONAL COORDINATING CENTER

End Stage Renal Disease National Coordinating Center
website: www.esrdncc.org
e-mail: ncc@ncc.esrd.net
(516) 209-5253
www.facebook.com/esrd.ncc
@esrdncc

Prepared by the National Patient and Family Engagement (N-PFE) Learning and Action Network (LAN), under the ESRD NCC. The ESRD NCC gratefully acknowledges the following ESRD Networks as sources for development of the content used in this resource: FMQAI: The Florida ESRD Network 7, Network 8, Inc., and Heartland Kidney Network 12.

This publication was developed under Contract Number HHSM-500-2013-NW002C, titled “End Stage Renal Disease National Coordinating Center (ESRD NCC),” sponsored by the Centers for Medicare & Medicaid Services (CMS), Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy.

NATIONAL LEARNING AND ACTION NETWORK
Approved by Patients for Patients

Get the Facts: Kidney Transplantation

Learn the facts about getting a kidney transplant and how it might affect you before you make decisions about your treatment.

Tool #1: What’s covered?

Transplant Facts Brochure Topics:

- What is a kidney transplant?
- What are the 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?

ESRD NCC
NATIONAL
COORDINATING
CENTER

Tool #1: Assess your peer’s needs

Ask open-ended questions

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

Tool #1: Support your peer’s needs

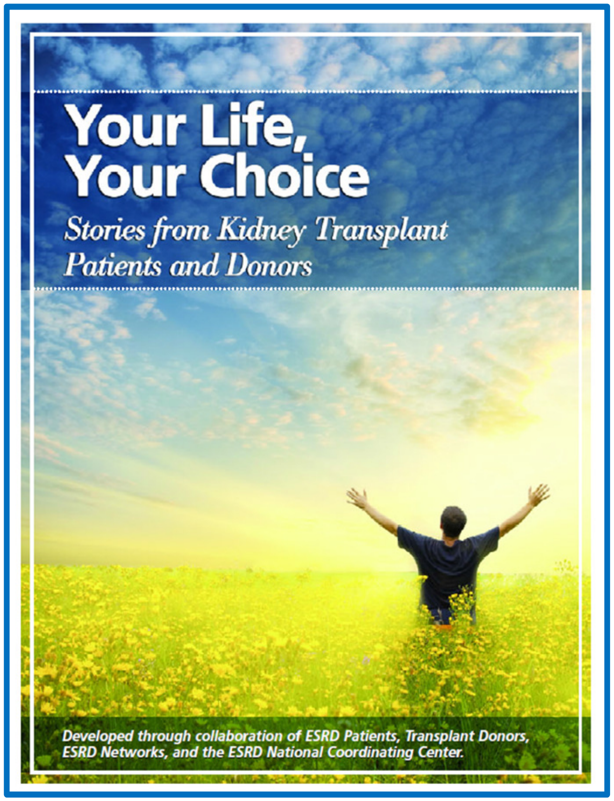
Your peer’s understanding of transplant:

- **Peer: Doesn’t have enough information**
  - ✓ **You: Share and review “Get the Facts” brochure**
- **Peer: Is asking for more clinical information**
  - ✓ **You: Connect peer to healthcare team for questions.**
- **Peer: 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/provide support.**
  - ✓ **Refer your peer to the healthcare team for help with taking the next steps.**

ESRD NCC
NATIONAL COORDINATING CENTER

Tool #2: “Your Life, Your Choice”

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



Your Life, Your Choice

Stories from Kidney Transplant Patients and Donors

Developed through collaboration of ESRD Patients, Transplant Donors, ESRD Networks, and the ESRD National Coordinating Center.

ESRD NCC
NATIONAL COORDINATING CENTER

Tool #2: “Your Life, Your Choice”

This tool can help you:

- **Navigate the transplant experience from 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.**
- **Discuss any concerns or barriers related to transplant with their care team.**
- **Helps mentors offer peers the opportunity to talk with someone in person that has been through the experience for added support.**

ESRD NCC
NATIONAL COORDINATING CENTER

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 patients to explore all treatment 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 peer's needs

Peer:
Expresses interest in having a family member consider becoming a living donor.

You:
Explain that this tool provides stories representing a variety of experiences of both recipients and donors.

Peer:
Mentions that she has heard that women are less likely to receive a transplant.

You:
Guide your peer to a story where she can read that gender is not an obstacle to exploring transplant as an option.

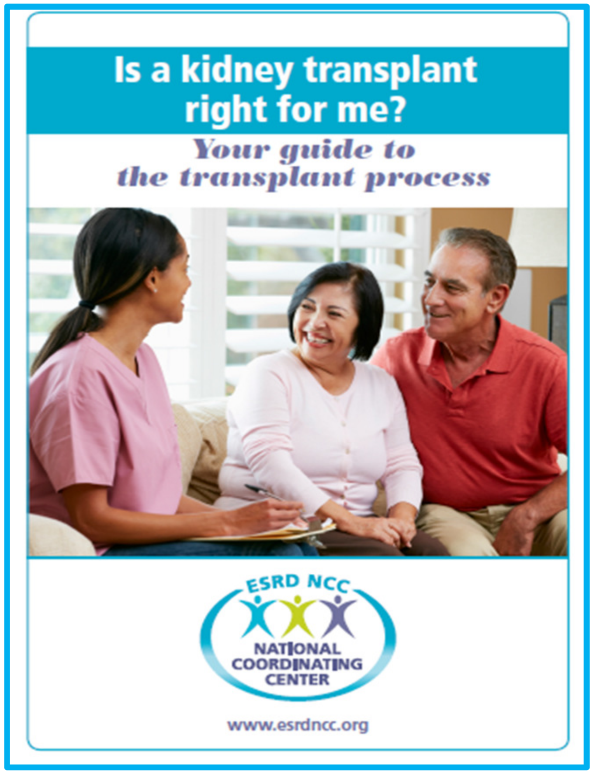
Peer:
Is concerned that because of his or her cultural background a transplant may not be a possibility.

You:
Guide your peer to a story, that helps your peer understand that transplant is a treatment choice for all cultures.

Tool #3: “Is a Kidney Transplant Right for Me?”

A detailed overview of the steps leading to

a transplant and care after surgery.



Is a kidney transplant right for me?

Your guide to the transplant process

ESRD NCC
NATIONAL
COORDINATING
CENTER

www.esrdncc.org

ESRD NCC
NATIONAL
COORDINATING
CENTER

Tool #3: What's covered?

Transplant Process Guide 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 peer has to wait for a non-living donor transplant.
- The multiple wait list option.

What is the surgery like?

- Surgery time and procedure.

ESRD NCC NATIONAL COORDINATING CENTER

Tool #3: What’s covered?

What happens after the surgery?

- Immediately after-surgery care.
- Ongoing and long-term healthcare needs required 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 your peer as he or she considers transplant.

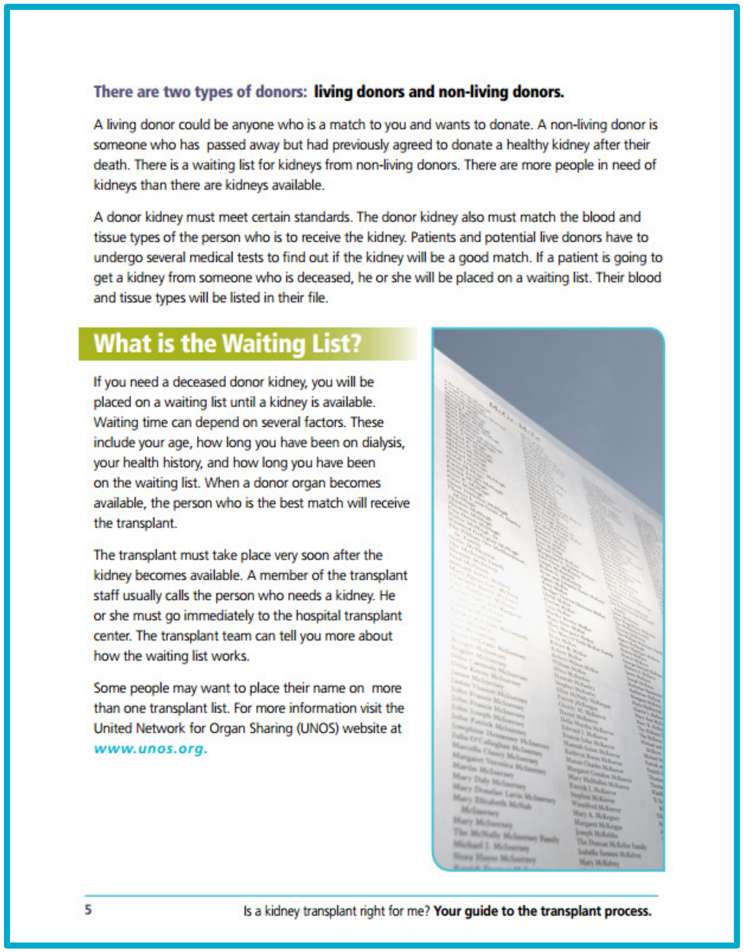
More questions?

- Questions to help your peer get needed information from his or her healthcare team.

ESRD NCC
NATIONAL
COORDINATING
CENTER

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

- **Peer**: Has questions about how to register for the kidney transplant waiting list.
  - ✓ **You**: Refer your peer 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?

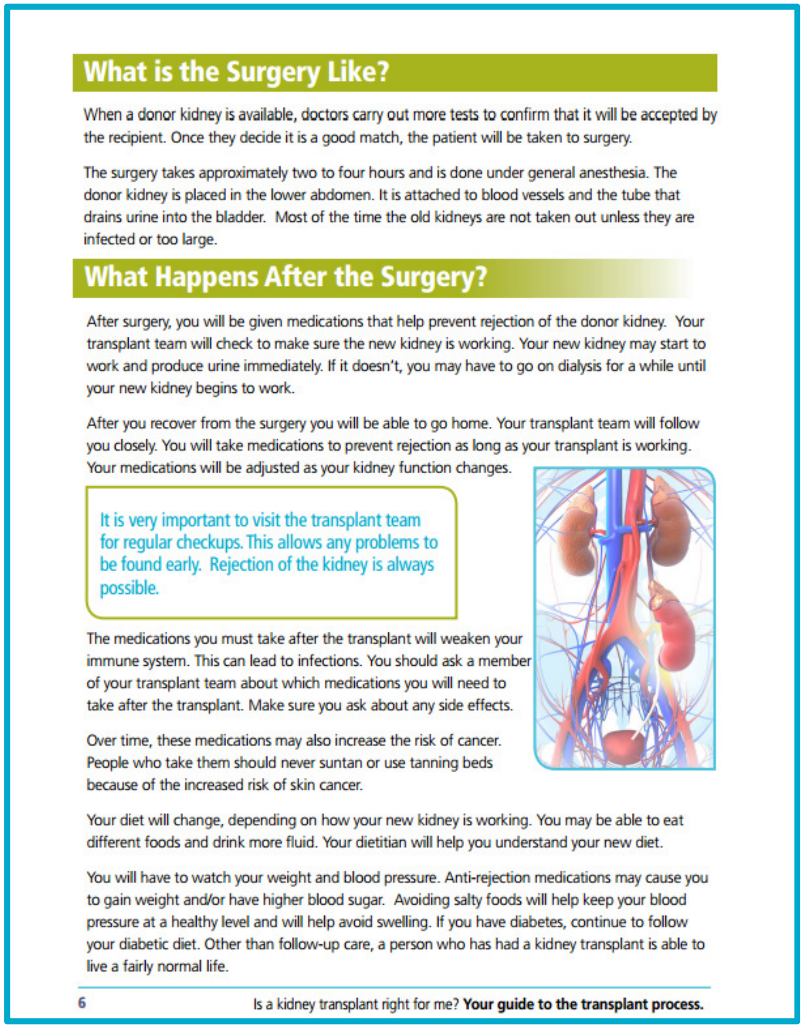
If you need a deceased donor kidney, you will be placed on a waiting list until a kidney is available. Waiting time can depend on several factors. These include your age, how long you have been on dialysis, your health history, and how long you have been on the waiting list. When a donor organ becomes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

5 Is a kidney transplant right for me? **Your guide to the transplant process.**

Tool #3: Assessing and supporting your peer'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 suntan 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.

6 Is a kidney transplant right for me? **Your guide to the transplant process.**

- **Peer** : Is concerned about the recovery process after transplant surgery.
  - ✓ **You**: Review with your peer the "What Happens After the Surgery" section (page 6) of the tool.

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

- **Peer** : Is worried about insurance coverage for a kidney transplant.
  - ✓ **You**: Guide your peer 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.

7 Is a kidney transplant right for me? **Your guide to the transplant process.**

PART 4

Tips to Remember

ESRD NCC
NATIONAL
COORDINATING
CENTER

Tips for supporting your peer

Once you have completed reviewing the transplant toolkit with your peer, it is up to your peer to take the necessary actions toward a transplant referral.

Remember:

- Encourage your peer to talk to a member of his or her care team about getting a transplant referral.
- Your peer 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 peer

Check in with your peer as often as you can to provide encouragement. If your peer:

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

ESRD NCC
NATIONAL COORDINATING CENTER

Tips for supporting your peer

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

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

Some important additional resources

- Your ESRD Network has several resources that can help you and your peers learn more about transplant and other treatment choices.
- Several renal organizations also provide educational resources for kidney patients.

ESRD NCC
NATIONAL
COORDINATING
CENTER

Some important additional resources

- Please see the Reference Guide for this module for a list of helpful website links.
- You can also check with your point of contact at your Center for additional resources.

ESRD NCC
NATIONAL COORDINATING CENTER

Thank you!

You have completed training to mentor

your peers on transplant.

You are now a certified

ESRD NCC

Transplant

Peer Mentor!

Next Steps

Where Do I Go From Here?

ESRD NCC
NATIONAL
COORDINATING
CENTER

What’s Next?

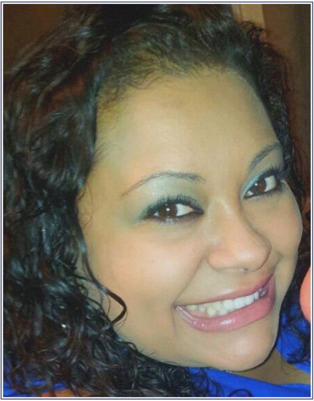
Congratulations on completing the Transplant Peer Mentorship Training Program Module!

- **Next, please complete the Module 3 Review Quiz to earn your completion badge.**
- **You are now ready to finish the course and earn your completion certificate.**
- **Share your completion certificate and review your plans with your facility point of contact. You will then be able to begin mentoring peers.**

ESRD NCC
NATIONAL
COORDINATING
CENTER

For More Information

Support Line: 516-209-5365
E-mail: ncc@ncc.esrd.net



Jeanine Pilgrim

Vicky Cash

ESRD NATIONAL COORDINATING CENTER (NCC)
1979 Marcus Avenue, Suite # 105
Lake Success, NY 11042-1072
Fax: (516) 326-7805
ncc@ncc.esrd.net
www.esrdncc.org
www.kcercoalition.org

ESRD NCC
NATIONAL COORDINATING CENTER

Thank you for taking our training course and sharing your learning experience with us!

REVIEW QUIZ (BOLD = ANSWER)

1. Your role as a peer mentor is to? (Select the best answer)
   a. Share your personal experiences as a new kidney patient.
   b. Offer educational resources and tools.
   c. Encourage your peer to be engaged and active in his or her care decisions.
   d. Tell your peer which decision they should make based on your experience.
   e. Help your peer get in touch with someone at his or her care team.
2. In order to be a transplant candidate there are criteria considered to assess if you’re eligible.
   a. A donor kidney must meet certain standards.
   b. A donor kidney must match the blood and tissue types of the person who is to receive the kidney.
   c. Patients and potential living donors have to undergo several medical tests to find out if the kidney will be a good match.
   d. All of the above
   e. None of the above
3. There is a waiting list for kidneys from living donors
   a. True
   b. False
4. The average life span for a donated kidney is 10 to 15 years.
   a. True
   b. False
5. 5. You should check in with your peer often to?
   a. Help connecting him or her with the healthcare team
   b. Reinforce information from the toolkit
   c. Provide support as he or she deals with the kidney care choice
   d. All of the above
   e. None of the above

ESRD NCC
NATIONAL COORDINATING CENTER