Peer Mentoring

Course 5: Discussing Transplant As an Option

ESRD NCC
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Course 5: Discussing Transplant as an Option

This course has four parts:

Course 5: Discussing Transplant as an Option

Welcome to Course 5!

This course will continue your training to become a peer mentor. The course will prepare you to talk with your peer about kidney transplant as a treatment choice.

You are not expected to be an expert in kidney transplant. That is the role of the healthcare staff at your facility. They will answer your peer’s questions. They will also support you in your role as peer mentor.

After taking this course, you will be able to:
- Describe what should be considered with a kidney transplant.
- Explain how you can support your peer in making treatment choices.
- Share resources with your peer.
- Identify resources on kidney transplant.

This course has four parts:
- Part 1: Learning the Basics of Kidney Transplantation
- Part 2: Talking with Your Peer about the Transplant Choice
- Part 3: Using Resources to Support Choices
- Part 4: Sharing Transplant Resources

Please read all four parts. You can also go back and re-read parts as you wish.

After you have finished, take the quiz about what you learned.

Part 1: Learning the Basics of Kidney Transplantation

Healthy kidneys remove extra fluid and waste from the blood. When kidneys can no longer do this, fluid and waste build up in the body. This condition is known as kidney failure. Another name for kidney failure is end stage renal disease. Kidney transplant is one treatment choice for kidney failure.

What is a kidney transplant?

Kidney transplantation is surgery to give someone a new kidney. The new kidney takes over the work that the failed kidneys cannot do.

The new kidney comes from another person. The person getting the kidney is called the recipient. The person giving the kidney is called the donor.

Donor = The person giving the kidney

The transplant may be the recipient’s first transplant. Or it may be a replacement for another transplanted kidney.

Only one kidney is transplanted. A person can live a healthy life with one working kidney.

Recipient = The person getting the kidney

Benefits of a Kidney Transplant

A kidney transplant is the only treatment that works 24 hours a day.

Here are reasons why someone might want to get a kidney transplant:

- Improved quality of life
- More freedom since dialysis treatments are no longer needed
- More energy
- Not as many diet restrictions

Types of Donors

A kidney donor can be a non-living donor or a living donor. The donor and the donor's kidney must meet certain standards to be used in a transplant. The kidney must also be a match for blood and tissue type.

Non-Living Donor

A non-living donor is someone who has passed away. He or she agreed to donate his or her healthy organs before passing away. Or the family of the donor agrees to donate the healthy organs of the family member.

More people need kidney transplants than there are donated kidneys. Anyone who chooses transplant from a non-living (cadaver) kidney donor has to be put on a waiting list. Time on the waiting list can depend on many factors, including:

- The recipient's blood type
- The recipient's age
- The recipient's health history
- The recipient's support system
- How long the person has been on dialysis
- How long the person has been on the transplant waiting list

Living Donor

A living donor is anyone who is a match to the recipient and wants to donate.

Living donors are tested to make sure that donating a kidney is safe for them. They are also tested to see if they are a good match to the recipient.

The waiting time can be shorter than the waiting time for a transplant from a non-living donor.

A person wanting a kidney transplant can learn about programs for living kidney donation from the healthcare team.

The Kidney Transplant Choice

A transplant is not an option for everyone. To be a candidate for transplant, a person has to be healthy enough to have the surgery. The person also must be able to take the medicines that will help his or her body to accept the new kidney.

The person's kidney doctor and healthcare team will help him or her get a referral to see a transplant team. The transplant team will check to see if he or she can get a transplant. They will meet with the person to share information. Topics will include the waitlist, tests that need to be done, and what will happen after the transplant. The transplant team will answer questions and describe the next steps.

Nephrologist = kidney doctor

A kidney transplant is only one treatment option. It is not a total cure for kidney failure. And it does not cure kidney disease. If a person has a chronic illness that caused kidney failure, having a transplanted kidney may not cure the illness.

Other things must be looked at when deciding on a kidney transplant. These include:

- Getting better after surgery
- Possible rejection of the kidney
- Side effects of medicines that keep the body from rejecting the kidney
- The possibility of added medical costs

Part 2: Talking with Your Peer about the Transplant Choice

Your peer will be making important decisions about his or her treatment. The choices your peer makes can affect his or her quality of life. The decisions can also affect his or her experience of care.

Let’s look at how you can help your peer as he or she makes important decisions.

Peer Mentoring – Discussing Kidney Transplants

Talk with your peer about a kidney transplant as a potential choice. Keep in mind that it is not the only option. A kidney transplant is not for everyone. Your role is to educate your peer about a kidney transplant as one of the choices.

Your Role as Your Peer Makes a Decision

1. Encourage your peer to connect with the healthcare team.

"2. Share educational resources on kidney transplant."

3. Check in often.

4. Celebrate if your peer talks about a transplant referral.

5. Continue to share information.

6. Offer support if transplant is not an option.

7. Share your personal experiences.

8. Urge your peer to get active in care decisions.

What if my peer does not want a transplant?

After you meet with your peer, he or she may not want to proceed at this point. That is okay!

Your peer may need more time to talk it over with family or friends.

Or transplant may not be a choice he or she wants to pursue. Everyone is different. What is right for one person is not always right for another. Transplant is not an option for everyone. Your peer may choose a different treatment. The best choice is the one that is right for him or her!

Your role is to give your peer information about this treatment choice. If you have done this, you will have succeeded as a mentor. Your peer can then decide if kidney transplant is the right choice for him or her.

Tips for Success

- Explore talking with your peer about transplant as a potential choice.
- Honor your peer’s decision if he or she does not want to talk about transplant. Remember, your peer has other treatment options to consider.
- Support your peer no matter what he or she chooses.

Part 3: Using Resources to Support Choices

As a peer mentor, you will share resources with your peer. This includes resources on kidney transplant. Your peer will then be able to ask questions. Your peer will also have the information he or she needs to make an informed decision about this treatment choice.

Make sure you are familiar with the resources before you meet with your peer. This will help you refer your peer to the appropriate pages. You will also be able to talk about questions your peer might have.

What should I do to share resources?

Here are general guidelines:

- Always begin with finding out your peer's understanding.
- Ask open-ended questions:
    - Are you interested in learning more about kidney transplants?
    - What do you know about kidney transplants?
    - What information have you received?
    - What questions do you have?

"What other information do you need?"

If your peer…

Has questions about a kidney transplant	Share resources with your peer. This will allow your peer to prepare questions for the healthcare team. Your peer may need time to think about the information. He or she may have questions later.
Is asking about clinical information	Ask him or her to contact the nurse on the healthcare team.
Is asking about the transplant process	Ask him or her to contact the social worker on the healthcare team.
Learns that transplant is not an option	Provide support as he or she deals with this news. Suggest that your peer talk with the social worker.

Tips for Success

- Be open to where your peer is in his or her journey. Your peer may want to talk about treatment options at another time.
- Immediately direct health questions to the healthcare team.

Let’s practice mentoring!

Matt received a kidney transplant six months ago. He is now a peer mentor at his dialysis facility. Matt has been paired with Tim. Tim wants more information on the kidney transplant referral process.

Matt sets up the first meeting. Tim prefers not to meet while he is on dialysis. Matt says that’s the only time he can meet. The dialysis facility is very noisy and has no place for Matt to sit. Matt comes in and stands next to Tim. Matt begins to share his experience about his transplant with Tim. The nurse interrupts to give Tim his medication. Matt continues to talk the whole time. Matt tells Tim that transplant is the best treatment option for him.

Was this a successful meeting? No!

What went wrong?

Matt did not listen to Tim when he said he didn’t want to meet while on dialysis. In fact, it looks like Matt didn’t listen to Tim at all. Matt didn’t sit down. He talked over the noise and the nurse. And Matt told Tim which treatment to choose.

How could this have been a better meeting?

Matt should have:

- Agreed on a time and place that worked for Tim.
- Picked a place that was quiet and had no distractions.
- Sat, so he could make eye contact with Tim.
- Listened to Tim.
- Given Tim resources to read on kidney transplant.

“Do you mind talking while you are getting dialysis?”

As a peer mentor:

- Ask if it is a good time to talk with your peer. If your peer says that it isn’t a good time, ask to set up another time.
- Ask if your peer is comfortable talking with you while on dialysis. If not, ask if there is a better place and time to sit and talk.
- Listen to what your peer says.
- Do not tell your peer which treatment to choose.

Part 4: Sharing Transplant Resources

You can share these three resources about kidney transplant. The resources may empower your peer to make an informed decision about getting a kidney transplant.

You are not expected to know all of the information in the resources. Instead, you need to:

- Know what resources are available for your peer.
- Understand what your peer can learn from the resources.
- See how the resources can help you in your role as a peer mentor.

For any questions, you can encourage your peer to talk with the healthcare team.

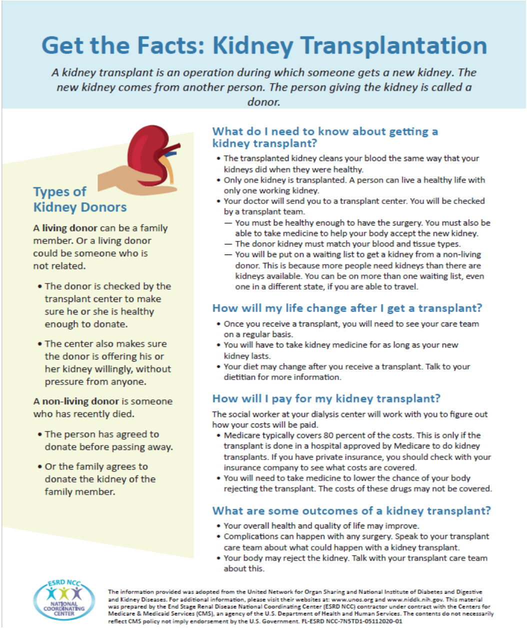
1. Get the Facts: Kidney Transplantation

The first resource is a flyer that covers questions your peer might have as he or she begins to think about a kidney transplant.

Your peer will learn what a kidney transplant is. Your peer will also read about what to expect after a transplant as well as the benefits of a transplant.

This resource will allow you to:

- Talk about kidney transplants.
- Find out what your peer already knows about kidney transplants.
- Learn if your peer needs more information at this point.



Get the Facts: Kidney Transplantation

A kidney transplant is an operation during which someone gets a new kidney. The new kidney comes from another person. The person giving the kidney is called a donor.

Types of Kidney Donors

A **living donor** can be a family member. Or a living donor could be someone who is not related.

- The donor is checked by the transplant center to make sure he or she is healthy enough to donate.
- The center also makes sure the donor is offering his or her kidney willingly, without pressure from anyone.

A **non-living donor** is someone who has recently died.

- The person has agreed to donate before passing away.
- Or the family agrees to donate the kidney of the family member.

What do I need to know about getting a kidney transplant?

- The transplanted kidney cleans your blood the same way that your kidneys did when they were healthy.
- Only one kidney is transplanted. A person can live a healthy life with only one working kidney.
- Your doctor will send you to a transplant center. You will be checked by a transplant team.
  - You must be healthy enough to have the surgery. You must also be able to take medicine to help your body accept the new kidney.
  - The donor kidney must match your blood and tissue types.
  - You will be put on a waiting list to get a kidney from a non-living donor. This is because more people need kidneys than there are kidneys available. You can be on more than one waiting list, even one in a different state, if you are able to travel.

How will my life change after I get a transplant?

- Once you receive a transplant, you will need to see your care team on a regular basis.
- You will have to take kidney medicine for as long as your new kidney lasts.
- Your diet may change after you receive a transplant. Talk to your dietitian for more information.

How will I pay for my kidney transplant?

The social worker at your dialysis center will work with you to figure out how your costs will be paid.

- Medicare typically covers 80 percent of the costs. This is only if the transplant is done in a hospital approved by Medicare to do kidney transplants. If you have private insurance, you should check with your insurance company to see what costs are covered.
- You will need to take medicine to lower the chance of your body rejecting the transplant. The costs of these drugs may not be covered.

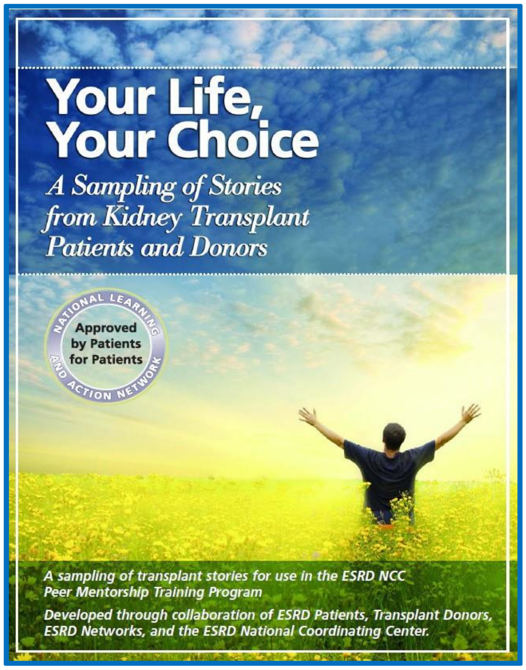
What are some outcomes of a kidney transplant?

- Your overall health and quality of life may improve.
- Complications can happen with any surgery. Speak to your transplant care team about what could happen with a kidney transplant.
- Your body may reject the kidney. Talk with your transplant care team about this.

The information provided was adopted from the United Network for Organ Sharing and National Institute of Diabetes and Digestive and Kidney Diseases. For additional information, please visit their websites at: www.unos.org and www.niddk.nih.gov. This material was prepared by the End Stage Renal Disease National Coordinating Center (ESRD NCC) contractor under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents do not necessarily reflect CMS policy not imply endorsement by the U.S. Government. FL-ESRD NCC-7N5TD1-05112020-01

2. Your Life, Your Choice

The second tool is a transplant story booklet. It includes stories from transplant recipients and donors, told in their own words. These real-life stories address what patients might think of as barriers to getting a kidney transplant. Barriers could include age, gender, race or ethnicity.



Your Life, Your Choice

A Sampling of Stories from Kidney Transplant Patients and Donors

National Learning and Action Network
Approved by Patients for Patients

A sampling of transplant stories for use in the ESRD NCC Peer Mentorship Training Program

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

Your peer will be able to learn more about the transplant process from the perspective of individuals who have already gone through it. Your peer might feel motivated to explore all treatment options, including kidney transplant.

How can you use these stories? Here are a few examples.

If your peer says, “I’m too old to get a transplant”:

- You can direct him or her to a story related to age, where a person with a transplant talks about how he or she worked through the issue.

If your peer has heard that women are less likely than men to receive a transplant:

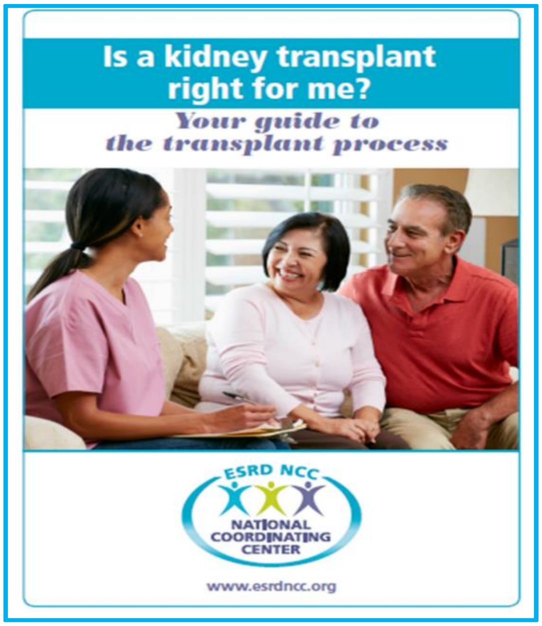
- You could guide her to a story from a female transplant recipient.

If your peer is interested in asking a family member to consider donation:

- The booklet includes a story from a living donor and recipient.

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

The third resource is meant for your peer if he or she is thinking about a transplant. The guide includes a complete review of the steps involved in a kidney transplant.



Is a kidney transplant right for me?

Your guide to the transplant process

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Your peer will learn what happens from evaluation by the transplant team through surgery. He or she will also learn about care after surgery and life with a transplant.

This resource will allow you to:

- Share details of what happens before, during, and after transplant.
- Review common questions with your peer.
- Show your peer where to get more information.

Tips for Success

- Share materials with your peer. Keep in mind that it is up to your peer to take the steps toward a transplant referral.
- Direct health questions to the healthcare team.
- Help your peer connect with the healthcare team or the Network for support and more resources.

Where to Find Resources on Kidney Transplant

You will find the resources listed in this course by going to the home page of this program. Click on the Resource button to find the links. Check to see if your dialysis facility can help to print these for you.

Next Steps in the Training Program

Congratulations on completing Course 5, Discussing Transplant as an Option!

Next, **please complete the Course 5 Review Quiz.**