

**Patients
Helping
Patients
Learn
About
Kidney
Care
Choices**

**MODULE 3A
REFERENCE
GUIDE**



**End Stage Renal Disease
National Coordinating Center
2015 Edition**



Discussing Transplant as an Option

Discussing Transplant as an Option

Introduction

Welcome to Module 3A, Discussing Transplant as an Option. This module has four parts:

- **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

This module is designed to help you continue your training to become a peer mentor at your dialysis center, focusing on kidney transplant as an option.

Think back to when you were first told about your diagnosis that your kidneys were failing. Were you overwhelmed? Did you feel alone with this problem? Was it hard to remember and understand what you were being told? Maybe you felt like you received too much information in too short a time.



Looking back, do you feel that important information was not provided to you?



Discussing Transplant as an Option

A newly diagnosed kidney patient has 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?

The decisions that have to be made based on these questions can affect your peer's quality of life and experience of care.

In your role as a mentor, you can help a new kidney patient with these important choices by sharing your personal experiences and offering educational resources and tools. You can encourage your peer to get engaged and active in care decisions. You can also help your peer connect with a member of his or her dialysis care team or someone at the ESRD Network for additional support and resources.

When you finish this module, you will be prepared to talk with your peers about kidney transplantation.

...Let's get started!





This image shows a full page of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page, providing a template for handwriting practice or general note-taking. There are no margins, text, or other markings present.



Discussing Transplant as an Option

Part 1: Learning the Basics of Kidney Transplantation

What is a Kidney Transplant?

Healthy kidneys remove excess fluid and waste from your blood. When your kidneys lose their filtering ability, fluid and waste accumulate in your body — a condition known as kidney failure or end stage renal disease (ESRD). A kidney transplant is one of the treatment choices for kidney failure.

Kidney transplantation is a surgery in which a person whose kidneys have failed receives a new kidney. This may be a person's first transplant, or it may be a replacement for another transplanted kidney. The new kidney takes over the work of cleaning the blood. The new kidney comes from another person and only one kidney is transplanted. A person can live a healthy life with one working kidney.

Transplantation and Donors

There are two types of kidney donors, **living donors** and **non-living donors**.

Someone who has passed away, and has previously agreed to donate his or her healthy organs or whose next of kin has agreed to donate the healthy organs of the family member.

Non-Living Donor

Anyone who is a match to the recipient and who wants to donate.

Living Donor



Discussing Transplant as an Option

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

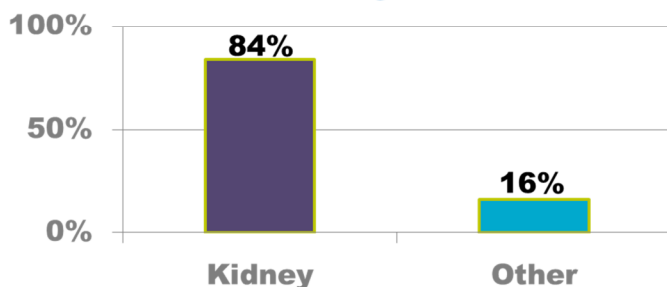
In 2014, more than 17,000 kidney transplants took place in the U.S. More than 11,500 of those used kidneys from non-living donors, and more than 5,000 came from living donors.

Transplant Facts

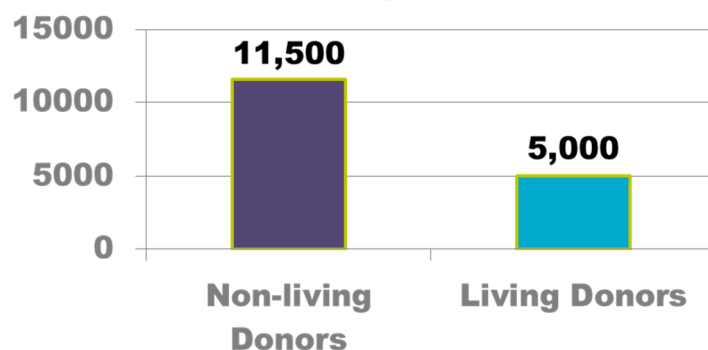
Transplant is not an option for everyone. To be a candidate for transplant, an individual has to be healthy enough to have the surgery and must be able to take the medications that will help ensure that his or her body accepts the new kidney. Your peer's nephrologist and care team will help him or her get a referral to see a transplant team. The transplant team will assess if he or she is eligible for a transplant, and they will help answer any questions your peer might have about the process.

The donor and the donor's kidney must meet certain standards in order to be used in a transplant. The kidney must also be a match for your peer's blood and tissue type.

**U.S. Organ Transplant
Waiting List**



U.S. Kidney Transplants





Discussing Transplant as an Option

Waiting for a Kidney Transplant from a Non-Living Donor

There are more people who need kidney transplants than there are donated kidneys. Anyone who chooses transplant from a non-living kidney donor has to be placed on a waiting list. Time on the waiting list can depend on several factors, including the recipient's:

- Blood type
- Age
- Health history
- Support system
- Length of time on dialysis
- Length of time on the transplant waiting list

The national waiting list follows strict guidelines to make sure donated organs are distributed fairly. More than 3,000 new patients are added to the kidney waiting list each month.

Waiting for a Kidney Transplant from a Living Donor

Waiting time for a transplant from a living donor is based on the time it takes to evaluate the people who are willing to donate. Living donors are fully tested to make sure that donating a kidney is safe for them and that they are a good match to the recipient. This waiting time is usually shorter than the waiting time for a transplant from a non-living kidney donor. There are several programs for living kidney donation that the peer should learn about from their dialysis care team, in order to fully understand his or her options.





Discussing Transplant as an Option

Why is Transplant an Important Treatment Choice?

A kidney transplant is the most effective treatment for kidney failure. It is the only treatment that will work 24 hours a day. It's important to remember that kidney transplant is only one of your peer's treatment options. It is not a total cure for kidney failure, and it doesn't cure kidney disease. If an individual has a chronic illness that caused kidney failure, having a new transplanted kidney may not cure the illness.

The average life span of a donated kidney is 10 to 15 years. If the transplanted kidney stops working, your peer may be able to get back on the waiting list for another kidney. He or she may also resume dialysis.





Discussing Transplant as an Option

Some of the **positive outcomes** of kidney transplant are improved health and quality of life, including:

- Greater freedom, since dialysis treatments are no longer necessary.
- Increased energy levels.
- Fewer diet restrictions.

There are important considerations about kidney transplant that your peer should consider, including recovering from the surgery, possible rejection of the kidney, side effects of anti-rejection medication, and the possibility of additional medical expenses.





Discussing Transplant as an Option

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. The goal is to educate your peer about transplant as an option.



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Discussing Transplant as an Option

Part 2: Introduction to the Kidney Transplantation Resource Toolkit

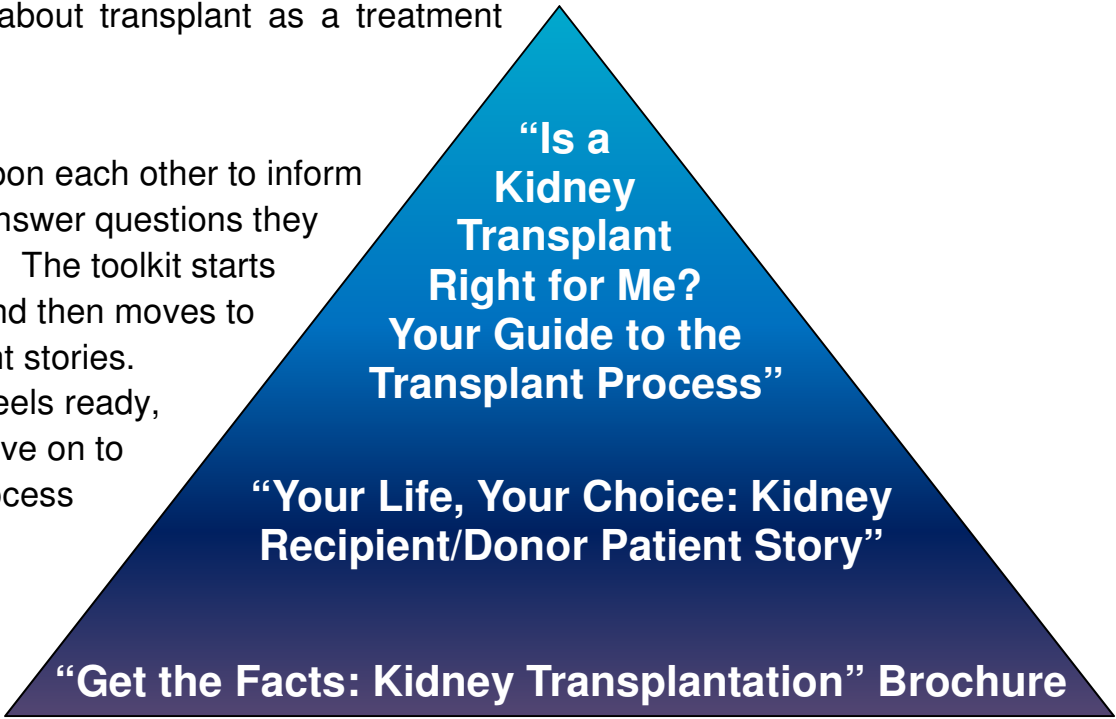
Now let's learn about the materials in your toolkit that will help you mentor patients about this kidney care choice. Your resource toolkit for kidney transplantation includes three educational resources.

The first resource is **“Get the Facts: Kidney Transplantation,”** a booklet that provides basic and important information needed when anyone is considering transplant as an option. The tool covers what a kidney transplant is, how it works, where donor kidneys come from, outcomes and considerations for kidney transplant, and important lifestyle changes,

The second tool is **“Your Life, Your Choice,”** a transplant story booklet. It contains personal accounts of the transplant experience from kidney transplant recipients and donors. The stories focus on positive experiences that may be helpful to review with your peer if he or she has some concerns about considering transplant as an option.

The third resource is **“Is a Kidney Transplant Right for Me? Your Guide to the Transplant Process.”** This tool is a complete review of the steps involved in kidney transplant, from evaluation by the transplant team through surgery, and how life changes after receiving a transplant. It is meant for peers who are ready to start thinking about transplant as a treatment option.

The tools build upon each other to inform your peers and answer questions they are likely to have. The toolkit starts with the basics and then moves to a review of patient stories. Once your peer feels ready, he or she can move on to the transplant process guide.



**“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” Brochure

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Discussing Transplant as an Option

Part 3: Using the Resource Toolkit

Now that you have a general idea of the tools, let's go into more depth about each one.

Get the Facts: Kidney Transplantation

This tool reviews questions an individual might have as he or she begins to consider a kidney transplant. It is a very basic review of facts and brings into focus the benefits and other considerations of transplant. Topics in the "Get the Facts" brochure include:

- What is a kidney transplant?
- Information about getting a transplant.
- Life changes after transplant.
- Transplant outcomes and considerations.
- Types of donors.

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




**End Stage Renal Disease
National Coordinating Center**

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Get the Facts: Kidney Transplantation



What is a kidney transplant?

- A kidney transplant is a surgery in which a person with kidney failure receives a new kidney. The transplanted kidney then cleans your blood in the same way that your kidneys did when they were healthy.
- The new kidney comes from another person. Only one kidney is transplanted. A person can live a healthy life with only one working kidney.
- Kidney transplant is one of your treatment options. It is not a total cure for kidney failure.
- Not everyone can receive a transplant.

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

- Your medical practitioner will send you to a transplant center. You will be evaluated by a transplant team to make sure you are a good prospect for a kidney transplant.
- You must be healthy enough to have the surgery. You must also be able to take the medications which help your body accept the new kidney.
- Talk to your care team to learn more about how to start the process for a transplant referral and evaluation.
- Donor kidneys come from living donors and non-living donors. A non-living donor is a person who has recently passed away but has donated a healthy kidney. A living donor could be anyone who is a match to you and wants to donate.

The donor kidney must match the blood and tissue types of the person who is to receive the kidney.

- More people need donor kidneys than there are kidneys available. There is a waiting list for kidneys from non-living donors. 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 medications 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?

- Medicare typically covers 80% of the costs if the transplant is done in a hospital approved by Medicare to do kidney transplants. Coverage by private insurers varies.
- Your transplant team will talk to you about the possibility of your body rejecting the transplanted kidney. Part of the cost of anti-rejection medicines may not be covered. These may be expensive.
- A transplant social worker or financial advisor will work with you to determine how your costs will be covered.

What are some outcomes of a kidney transplant?

- Your overall health and quality of life will likely improve.
- You may be less tired and have more energy.
- You have more freedom because you no longer need dialysis.

What are some things I should consider about having a kidney transplant?

- With any surgery, there are possible complications. This is true for transplant surgery as well. Speak to your transplant care team.
- There is a risk that your body may reject the kidney. Talk with your transplant care team about possible risks.
- You will have to take anti-rejection medications daily after a kidney transplant. They may have side effects.

The following organizations provide resources and additional information about kidney transplantation:

- United Network for Organ Sharing www.unos.org
- National Institute of Diabetes and Digestive and Kidney Diseases www.niddk.nih.gov



Discussing Transplant as an Option

You may use this tool to open up discussion, find out what your peer already knows about kidney transplant, and learn if your peer needs more information at this point.

Always start with finding out your peer's understanding of the topic. Ask your peer open-ended questions:

- What do you know about transplantation?
- What information has been given to you?
- What questions do you have, or what other information do you need?

If your peer doesn't have enough information:

- Share and review the "Get the Facts" brochure.

If your peer is asking for more clinical information:

- Connect him or her with the healthcare team.

If your peer says he or she needs more time to think it over:

- Provide the brochure and say that you will check back at a later date.





Discussing Transplant as an Option

“Your Life, Your Choice”

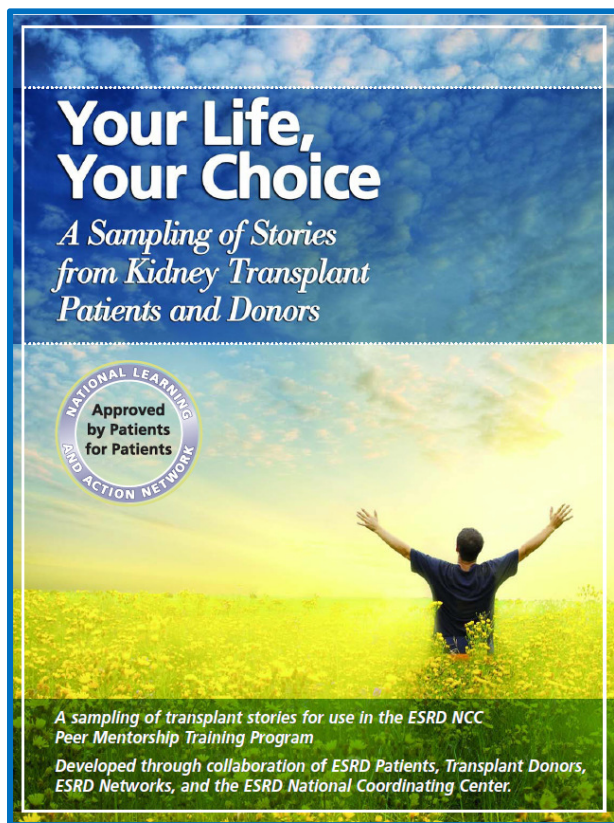
The second tool is a compilation of stories from transplant recipients and donors, told in their own words. It shares the perspective of individuals who have already gone through this process and highlights their positive experiences.

The “Your Life, Your Choice” transplant stories booklet will help your peers:

- 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.
- Feel more comfortable considering transplant as an option.

This tool can help you as a mentor to:

- Help your peer identify any concerns he or she has related to transplant, so these concerns can be discussed with the healthcare team.
- Offer peers the opportunity to talk with someone who has been through the experience.





Discussing Transplant as an Option

These real-life stories were developed to address what patients might think of as barriers to getting a kidney transplant, including age, gender, race or ethnicity. They were designed to motivate kidney patients to explore all treatment options, including kidney transplant. How can you use these stories? Here are a few examples.

Your peer may say, “I’m too old to get a transplant.”

- You can direct him or her to a story related to age, in which a transplant patient discusses how he or she worked through the issue.

Your peer has heard that women are less likely than men to receive a transplant.

- Guide her to a story from a female transplant recipient.

Your peer might think transplant isn’t an option because of his or her culture.

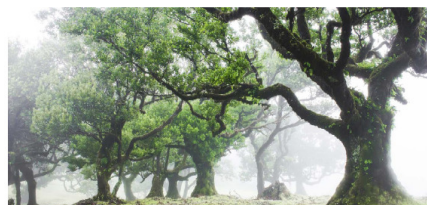
- There are stories in the booklet from a variety of races and ethnic groups.

Your peer is interested in asking a family member to consider donation but might not understand the donor’s experience.

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

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This booklet contains real-life stories of kidney transplant recipients and donors, as told in their own words.

The stories were created as a way to share positive perspectives on kidney transplant as a treatment choice. They are designed to motivate and empower kidney patients, their families, and care partners to explore all treatment choices, including kidney transplant.

The booklet does not provide medical advice or information, but rather a first-hand narrative from the patient's perspective.

Compiled and produced by the End Stage Renal Disease (ESRD) National Coordinating Center (NCC), in collaboration with participating ESRD Networks.

We are grateful to the transplant recipients and donors who graciously shared their stories.



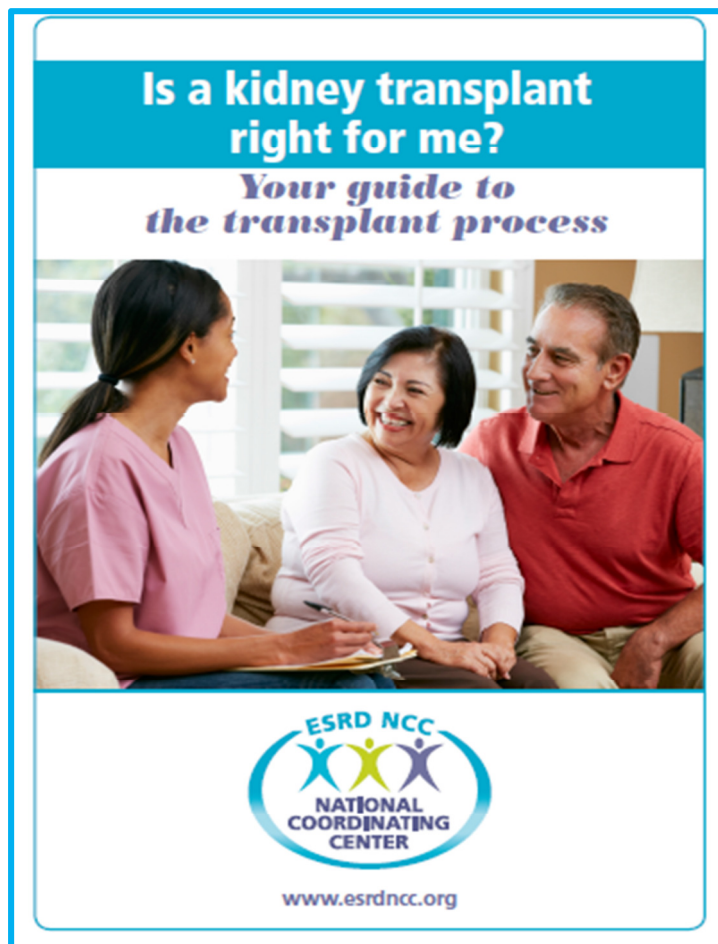
Discussing Transplant as an Option

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

After your peer has reviewed the transplant story booklet and has worked through concerns about considering transplant as an option, you may want to move on to discussing the transplant process. The third tool provides more detail about the steps involved in getting a transplant, care after surgery, and life with a transplant.

Topics covered in the transplant process guide include:

- An overview of transplant as an option.
- What is a transplant center?
- The new Kidney Allocation System.
- Types of kidney donors.
- The waiting list for a non-living donor transplant, and the multiple wait list option.
- What is the surgery like?
- What happens after the surgery?
- After-surgery care.
- Ongoing and long-term healthcare needs after a transplant.
- Cost of a kidney transplant.
- Members of the transplant team.
- Where to get more information about their questions.





Discussing Transplant as an Option

Make sure you know the guide and are familiar with the different sections before you meet with your peer. You will be better able to talk about particular questions or to refer your peer to the appropriate pages with information to help them.

For example, your peer may have questions about the transplant waiting list.

- You can direct him or her to page 5, on which this topic is discussed.

What if your peer is concerned about the recovery process after the surgery?

- Review “What Happens After the Surgery?” on page 6 of the tool.

Another question may be about insurance coverage or the cost of medications.

- Guide your peer to “How Much Does a Kidney Transplant Cost” on page 7.

Being familiar with the transplant process guide can help you connect your peers to the information they need. Always remember to immediately direct health questions to the healthcare team for the best answers, and continue to support your peer through this important choice in their kidney care.

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

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How Much Does a Kidney Transplant Cost?	7
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Do not be afraid to ask ANY questions!

Please feel free to talk with a member of your care team or contact your local ESRD Network for more information. For help finding your Network visit www.esrdncc.org.

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Discussing Transplant as an Option

Part 4: Tips to Remember

Now, let's review some important tips to help you be successful in your role. Once you have completed reviewing the transplant toolkit with your peer, it is up to your peer to take the necessary steps toward a transplant referral.

Remember:

- Encourage your peer to talk to a member of his or her care team about getting a transplant referral.
- If your peer chooses to talk to the care team about getting a transplant referral, celebrate this choice and be encouraging.
- Your peer may not want to proceed at this point, and that is OK! He or she 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. You have succeeded in your role as a mentor by providing him or her with important information, so he or she can make an educated decision about transplant as an option.





Discussing Transplant as an Option

Here are some more tips for supporting your peer. Check in 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 the way...

- Continue to share information from the toolkit, so your peer can prepare questions for the healthcare team. Even when you have finished sharing the tools, your peer may need time to process the information and may have questions later on.

Learns that transplant is not an option...

- Provide support as he or she deals with this news.

Always remember there are other options for treatment that your peer can consider. If transplant is not the option for your peer, that is okay. **The best choice is the one that is right for him or her!**

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. Feel free to share this information with your peers so they can do additional research on their own. You can also ask your point of contact at your center for additional resources and for any support you might need throughout the mentoring process.

The following organizations provide resources and additional information about kidney transplantation:

United Network for Organ Sharing
www.unos.org

National Institute of Diabetes and Digestive and Kidney Diseases
www.niddk.nih.gov

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Discussing Transplant as an Option

Next Steps

Congratulations! You have successfully completed Module 3A.

Please complete the Module 3A: Discussing Transplant as an Option Review Quiz and provide your results to your facility point of contact.

Once you complete the Review Quiz, you will be a certified ESRD NCC Transplant Peer Mentor! Your point of contact will let you know what tools you need to review to support your mentorship program. You can review your plans with your facility point of contact, and get ready to begin mentoring peers.

Thank you for taking our training course! For additional information, contact us at ncc@ncc.esrd.net.



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Discussing Transplant as an Option

Review Quiz Questions

Please answer the following questions to earn your Module 3A completion badge. You can review your quiz results with your facility point of contact for this peer mentoring program.

1. Your role as a peer mentor is to? (Select which is NOT true):

- ☐ 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.
- ☐ Tell your peer which decision they should make based on your experience.
- ☐ 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 donor kidney must meet certain standards.
- ☐ A donor kidney must match the blood and tissue types of the person who is to receive the kidney.
- ☐ Patients and potential living donors have to undergo several medical tests to find out if the kidney will be a good match.
- ☐ All of the above.
- ☐ None of the above.

Continue to next page.



Discussing Transplant as an Option

3. There is a waiting list for kidneys from living donors

☐ True

☐ False

4. The average life span for a donated kidney is 10 to 15 years.

☐ True

☐ False

5. You should check in with your peer often to?

☐ Help connecting him or her with the healthcare team.

☐ Reinforce information from the toolkit.

☐ Provide support as he or she deals with the kidney care choice.

☐ All of the above.

☐ None of the above.



Discussing Transplant as an Option

Review Quiz Answers

BOLD = CORRECT ANSWER

1. **Your role as a peer mentor is to? (Select which is NOT true):**

- ☐ 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.
- ☒ **Tell your peer which decision they should make based on your experience.**
- ☐ 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 donor kidney must meet certain standards.
- ☐ A donor kidney must match the blood and tissue types of the person who is to receive the kidney.
- ☐ Patients and potential living donors have to undergo several medical tests to find out if the kidney will be a good match.
- ☒ **All of the above.**
- ☐ None of the above.

Continue to next page.



Discussing Transplant as an Option

3. There is a waiting list for kidneys from living donors

☐ True

☒ False

4. The average life span for a donated kidney is 10 to 15 years.

☒ True

☐ False

5. You should check in with your peer often to?

☐ Help connecting him or her with the healthcare team.

☐ Reinforce information from the toolkit.

☐ Provide support as he or she deals with the kidney care choice.

☐ All of the above.

☒ None of the above.



Discussing Transplant as an Option



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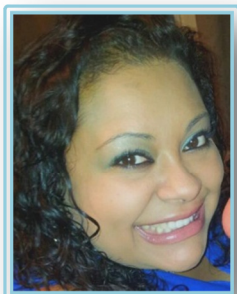


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