Coaching to Support Kidney Care Choices
Transplant as a Treatment Option

April, 2019

Expand skills. Share Knowledge. Empower Patients.
What will be covered in this Module?

Part 1: Kidney Transplant Facts
Part 2: Kidney Transplant Options
Part 3: Navigating the Kidney Transplant Steps
Part 4: Transplant Resource Toolkit
Part 5: Tips and Suggestions
Learning Objectives

At the completion of this activity the learner will be able to:

- List the ESRD Network roles and responsibilities
- Understand the “Patient Health Coach” role in the promotion and education of transplant
- Discuss steps towards transplant
- Describe the two forms of getting a kidney transplant
- Identify three benefits of transplant
- Identify who may be a potential candidate for transplant
- Utilize the training materials identified in this program to talk with patients about transplant options
- Share with other staff members information on Transplant options and how to use the resource toolkit
Network Role and Responsibilities

ESRD Networks are critical to achieving CMS goals for healthcare transformation and improving the patients experience of care by:

- Being leaders, motivators, and organizers
- Producing partnerships and collaboration within the ESRD community
- Promoting outreach and education
- Collecting, analyzing and monitoring data to measure achievement
- Collecting and sharing best practices
- Providing emergency preparedness services for the ESRD community
- Support patients and facilities in resolving grievances

CMS 5 Year Transplant Goal:
- By 2023, increase the number of ESRD patients dialyzing at home to 30% from the 2016 national average of 18.5% (CMS statement of work 2018)
Helping the patient make important choices

Renal patients need unbiased, factual information to make decisions that can affect their quality of life and experience of care.

Patients must be open and ready to process information

What is your role as a Patient Coach?

- Engage patients in discussion to determine knowledge of Transplant
- Provide resources
- Arrange an interaction with a current transplant waitlisted patient to share their perspective
- Refer patients to a member of the healthcare team
- Be available when questions arise - BE POSITIVE
Why is the “Patient Health Coach” so Important?

YOU are in a unique position to be:

• Viewed as an expert
• A trusted partner in the patient’s care
• Have open discussions during the patient’s treatment
• Encourage patients to be engaged and active in his or her care decisions

• A resource provider
  – Printed educational materials
  – Referral to a Social Worker, Nephrologist, or Healthcare Team Member
  – Provide assistance with electronic tools and resources as possible.
Part 1: Kidney Transplant Facts
What is 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
- Transplant is a treatment option, but is not a cure for ESRD
What are the two primary kidney transplant options?

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 donor candidate, matches and wants to donate.

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

750,000 people affected by ESRD in the US

100,000 ESRD patients in the waitlist

20,161 ESRD patients transplanted
Transplant Facts

• The average waiting time for a non-living kidney transplant is 4 years, while the waiting time for a living donor kidney varies depending on how long it takes to assess and determine candidacy both the recipient and donor.

• In 2016, less than a third of kidney transplants were from living donors.

• In 2018, there were 21,167 kidney transplanted accounting for 58.9% of all organs transplanted this same year.

• A dual kidney-pancreas transplant is also available to some diabetic patients.

• The transplant 5-year survival rate for transplanted patients is over 80%.

• Transplant is considered the best treatment option due to longer survival rates, better quality of life and lower hospitalization rates compared to dialysis.
Transplant Facts

• In 2014, the Kidney Allocation System changed expanding the availability of kidney transplant to more individuals in need in a fairly and equitable way by making better use of available kidneys

• A Kidney Donor Profile Index (KDPI) is assigned to a donated kidney combining factors (e.g.: age of the kidney) that indicates the likelihood of transplant failure

• Higher KDPI scores are associated with shorter kidney lifespan, but are still functional kidneys. These kidneys could be ideal for older patients who estimated life expectation matches the life of the kidney
Part 2: Kidney Transplant Options
Who is a good transplant recipient candidate?

A person with advanced Chronic Kidney Disease (CKD) or End Stage Renal Disease (ESRD) who otherwise is in good health conditions is generally a good candidate for kidney transplant. Each transplant center evaluates each individual to determine their unique needs related to the transplant process.

- Each transplant center has an evaluation process
- Absolute and Relative exclusion criteria is determined by each transplant center and varies across the nation
- A person might be evaluated by multiple transplant centers to evaluate candidacy based on that transplant centers criteria
Healthcare Benefits of a Kidney Transplant

Improved Clinical Outcomes

• Restored kidney functions that can influence hemoglobin levels, fluid exchange regulation, bone and mineral metabolism, clean blood from excess waste products and minerals, among others

Improve Mortality Rates

• The life expectancy after kidney transplantation is 12-15 years versus the average life expectancy of 5-10 years dialysis

Lower Healthcare Costs

• Reduced hospitalizations due to infection, fluid overload and cardiovascular complications is seen after kidney transplantation
Patient Benefits of Kidney Transplant

- A kidney transplant is the most effective treatment and the only treatment that will work 24 hours a day
- Increase life expectancy
- Fewer diet and fluid restrictions, if any
- Possibly fewer medications
- Better quality of life
  - Greater freedom (no dialysis treatments)
  - Flexibility to work and continue school
  - Ability to travel
  - Increased energy levels
Considerations for Kidney Transplant

- A transplant doesn’t permanently restore kidney function or cure kidney disease
- Anti-rejection medication is needed daily to maintain transplanted kidney
- Surgery and recovery time should be planned
- Rejection of a transplanted kidney is possible
- Additional medical expenses
Understanding the Transplant Center

Transplant Centers are a specialized program within a hospital that are certified by the Center of Medicare and Medicaid Services (CMS) to perform the evaluation and surgery of transplanted organs, such as kidney transplant.

- As of March 2019, there are 253 certified transplant centers in the United States
- The clinical criteria to be a kidney transplant candidate varies from center to center
- Each transplant center works with an interdisciplinary team that includes, nephrologist, surgeon, dietitian, social worker, nurses, among others
- Patients visit the transplant center a number of times to be properly educated and assessed for candidacy
- A number of clinical tests and blood labs are taken to assure patients are ready in every aspect to receive a kidney transplant, as it is a mayor surgery
What is Living Donation?

Living Donation is when a person is willing to give one of their healthy kidneys to a person in need of a kidney. This is the most successful of all transplant procedures.

- One year after kidney transplant, 90-95% individuals who received a living donor kidney still had a healthy kidney as opposed to only 88% of individuals who received a non-living 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.
- Living donors are fully evaluated to:
  - Make sure that donating a kidney is safe for them.
  - Test that they are a good match to recipient.
The Paired Exchange Program is an option for when a living donor is not an exact match to the intended recipient, but can create a chain of compatible donor-recipient individuals who would benefit from finding a true match.

- There are multiple paired kidney exchange programs, also known as “kidney swap”.
- The chain can start with at least two pairs, but it could also include more.
- For a list of transplant centers participating in a Paired Donation Program, please visit: [https://unos.org](https://unos.org)
What is a non-living kidney donor?

A healthy kidney from someone who has recently passed away and is still working can be surgically implanted in someone with kidney failure.

- This is also known as *cadaveric* or *diseased* 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.
Who can be a donor?

Being a kidney organ donor is a completely voluntary decision that anyone could be interested in. However, the kidney of the donor needs to be healthy in order to proceed.

- In both instances, the overall health of the person (alive or dead) is considered.
- For living donors, the health and mental assessment process is extensive and comprehensive to assure that the person will remain in good health after the donation.
What is the transplant waitlist?

The waitlist is an equitable and systematic process where patients are added based on need and eligibility for the surgery and are given in order of priority and match as kidneys become available from diseased donors.

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

• Geographical proximity to transplant center
• 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
Part 3: Navigating the Kidney Transplant Steps
Steps towards a kidney transplant

CMS defines the steps a patient takes towards transplant as followed:

1. Patient *interest* in transplant
2. *Referral* call to transplant center
3. *First visit* to transplant center
4. Transplant center *work-up*
5. Successful transplant *candidate*
6. On *waiting list* or evaluated potential *living donor*
Helping patients move towards transplant

**Patient interest in transplant**

- Sometimes patients already know about transplant and will voice their interest.
- Sometimes patients need to be educated about transplant in order to trigger interest.
- Patients might have fears or have heard negative experiences that should be addressed with education for patients to become interested.
- Many patients have heard myths or false information that make them think they don’t want a kidney transplant.
- Your role: ASK and EDUCATE!
Helping patients move towards transplant

**Referral** call to transplant center

- Some transplant centers accept patients to self-refer, but others will require a referral from the dialysis center
- All patients who voice interest should be referred to a Transplant Center for evaluation
- The referral might be via phone, fax or a secure electronic platform
- Many transplant centers have their own specific form and list of documents to send with it to start the process
- Your role: COMMUNICATE with your interdisciplinary team and let them know that a patient is interested. You might be able to help with completing the referral call or fax at your facility
Helping patients move towards transplant

*First visit* to transplant center

- The first visit to the transplant center can be exciting, but also scary or intimidating for some patients
- Many patients forget about their appointments or might have transportation difficulties to get there
- Your role: ASSESS if the patient needs follow up reminders, transportation arrangements/resources, or simply words of encouragement
Helping patients move towards transplant

Transplant center *work-up*

- This step could take some time and overwhelm your patient.
- There will be many tests and appointments that your patient needs to follow up to be deemed a good candidate for a kidney transplant.
- Your Role: FOLLOW UP with your patient by remaining them about their appointment and tests they need by:
  - Identifying barriers and strategies to help the patient overcome the barriers
  - Provide guidance to the patient so they understand follow up instructions.
  - Work with your team to discuss where the patient is in the work up process during plan of care meetings.
Helping patients move towards transplant

Successful transplant *candidate*

- The transplant center team meets to discuss every patient when all the information is available from various tests and appointments.
- This meeting determines if the patient is a good candidate for kidney transplant.
- The transplant center usually notifies both, the patient and the dialysis unit.
- Your role: SHARE this information with your team, and make sure that the patient gets notified as well.
Helping patients move towards transplant

On *waiting list* or evaluated potential *living donor*

- After the transplant team identifies a patient as a good candidate, that patient gets added to the transplant waitlist.
- If they are waiting in a non-living donor, they will get transplanted once a kidney becomes available for them.
- If they are being evaluated for a living donor, the surgery is scheduled once the donor and recipient have completed evaluations.
- Your role: CELEBRATE with the patient and your team! Keep encouraging the patient to maintain their health status so that they remain at the transplant list.

This is the longest wait, keep giving them encouragement.
Part 4: Transplant Resource Toolkit
What materials are in the Transplant Resource Toolkit?

“Kidney Transplant Referral Guide” Pamphlet

“Is a kidney transplant right for me?” Booklet

“Transplant: Get the Facts” Brochure
Assess the patient’s need for education

Ask open-ended questions

- What do you know about transplant?
- What type of information have you received?
- What other information do you need?
Tool #1: “Get the Facts: Kidney Transplantation”

Conversation starter

Basic transplant information
- Defines what is a kidney transplant
- Explains basic initial questions that your patient might have
- Trifold available in English and Spanish

Considerations and Questions to assist your patient in collecting information to make informed treatment choices
Tool #2: “Is a Kidney Transplant Right for Me?”

Comprehensive Transplant Information

- In-depth explanation to most frequently asked questions
- Explains the steps before, during and after kidney transplant surgery
- Provides guided questions that patients should ask at the transplant center

- Tool #2 can also be complimented with *Your Life, Your Choices* that include a number of patient stories about kidney transplant
Using Tool #2 – “Is a Kidney Transplant Right for Me?”

**Patient:** Expresses interest in getting a kidney transplant to meet their needs and lifestyle.

**You:** Explain that this tool provides information regarding the process before, during and after a kidney transplant surgery.

**Patient:** Mentions that would really like a kidney transplant, but has no one to donate it to him or her.

**You:** Guide the patient to the types of donor section and explain that a kidney can also be received from a non-living donor.

**Patient:** Is concerned that he or she won’t be able to afford a kidney transplant.

**You:** Guide the patient the section “How much does a kidney transplant cost?”
Tool #3: “Kidney Transplant Referral Guide”

Clinical guide to absolute exclusion criteria for ESRD Network area transplant centers.

- Find the best possible transplant center that meets your patient’s needs in criteria
- Work with the Social Worker and Nephrologist to best help a patient get referred to a transplant center
- All patients should be referred when interested and let the transplant center determine suitability
Patient: Am I too old for a kidney transplant?

You: Review the age category for absolute exclusion criteria from the referral guide and discuss transplant centers within the region where patient does not fall within the age range for exclusion.

Patient: Can I refer myself for a kidney transplant?

You: Review the miscellaneous section of the referral guide to see which transplant centers within your region accept patient self referrals.
Additional online resources

Explore Transplant
https://exploretransplant.org/

National Kidney Foundation
https://www.kidney.org/transplantation

iChoose Kidney
http://ichoosekidney.emory.edu/

Allocation System Changes for Equity in kidNey Transplantation (ASCENT Videos)
Staff Video: http://ascenttotransplant.org/for-dialysis-facility-providers-and-staff/#staff-video
Part 5: Tips and Suggestions
Tips for Being Successful

Educate patients on Kidney Transplant
  • Share educational resources and tools with patients
  • Encourage patients to be engaged and active in his or her care decisions
  • Refer patients to a member of the healthcare team for more information and/or follow-up

Communicate with Facility leadership regularly about your discussions with patients
  • Contact your Facility Leadership or the ESRD Network for additional support and resources

Share best practice models and lessons learned with team members
Tips for Success

- Know your role as a Patient Health Coach, and keep your conversations focused on topics related to your role.
- Avoid talking about confidential issues, and respect others’ rights to confidentiality.
- Keep private all information you know about a patient.
- Accept people for who they are, and do not try to change what they believe or choose.
- Keep an open mind to differences and avoid judgment of others.
- Always suggest that the patient talk with their healthcare team if they have medical questions.
Support the patient’s understanding of kidney transplant

**Patient:** Doesn’t have enough information
- **You:** Share and review materials

**Patient:** Is asking for more clinical information
- **You:** Connect patient to other members of the healthcare team for questions.

**Patient:** Indicates that he or she needs more time to think it over.
- **You:** Provide materials and set time frame to revisit information and allow for questions. Refer the patient to other members of the healthcare team as needed
Following Up

Check in with the patient to see if he or she has questions or concerns about the information you reviewed.

- Discuss patients interest or concerns with their Nephrologist.
- Direct medical questions to the healthcare team.
- Consider having a current home dialysis patient visit patient to present their perspective.
- Touch base with patient at regular intervals to support interest, or provide additional resources as needed. Suggested follow-up every 15 – 30 – 45 – 60 days.
- Re-evaluate your approach on how to improve your follow-up system.
Final Thoughts…

• Everyone is different. What is right for one person is not always right for another.

• Choosing a Kidney Transplant as treatment option is a personal choice and may not be an option for everyone

• Patients will be evaluated by a transplant center to determine if they are a suitable candidate for kidney transplant

The best choice is the one that is right for the patient!
Important Additional Resources

Below are some of the organizations that have additional resources that can help you and the patients learn more about kidney transplant.

• Your ESRD Network – http://esrd.ipro.org/

• The ESRD National Coordinating Center - https://esrdncc.org/

• United States Renal Data System - https://www.usrds.org/

• United Network for Organ Sharing (UNOS) - https://unos.org/
Next Steps

• Complete the *Transplant as a Treatment Option Module* Review Quiz
• Share your success with your facility management
• Take additional modules to improve your knowledge on other topics and grow your Patient Health Coach status.
  – Home Dialysis as a Treatment Option, Vascular Access Planning, Incorporating Patients into QAPI, Patient Support Group
  – Print educational resources from each module
  – Familiarize yourself with the resources
• Develop a plan to share your knowledge with patients.
  – Schedule a visit to a Transplant Center Training to learn more about the transplant process
  – Utilize the toolkit resources
  – Talk to a successful home patient to learn more about their journey
Celebrate each success you have in talking with your patients, because with each interaction you are making a difference.

Thank you for your hard work and commitment to helping others!
You have completed training to coach on the topic of Discussing Transplant as a Treatment Options!