End-Stage Renal Disease
Network Program

Myths and Realities about Treatment Options

June 2020

Speakers

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Agenda

Introduction

Myths and Reality about Home Dialysis

- Why a kidney patient should consider Home Dialysis
- Educational Resources to address Home Dialysis Myths

Myths and Reality about Kidney Transplant

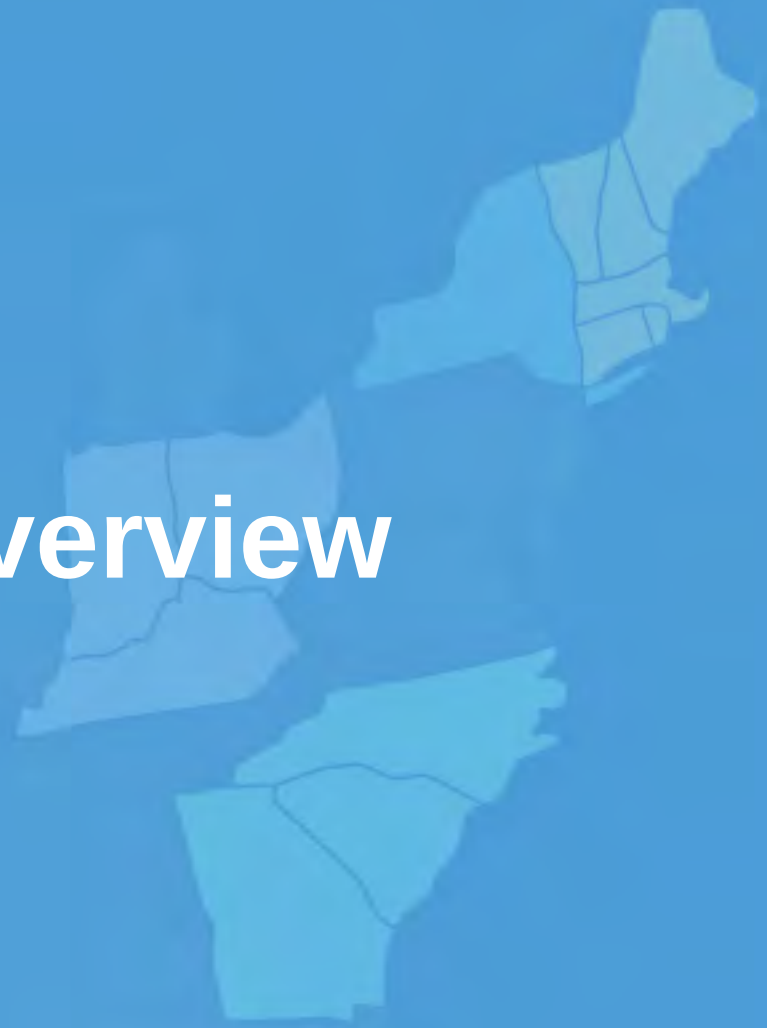
- Why a kidney patient should consider Kidney Transplant
- Educational Resources to address Kidney Transplant Myths

Closing Remarks

Introduction

- This recorded webinar is appropriate for both providers and patients.
- The ESRD Network has identified that some perceived challenges towards kidney transplantation and/or home dialysis utilization are based on myths.
- Myths are a widely held ideas that is based on stories. They tend to be false or partially false.
- During the following slides you will review varying myths regarding renal treatment options, and the reality or fact that addresses these misguided beliefs.
- If you are a provider, you may print the accompanied slides and share with patients as a handout or a collection of prints through your facility or bulletin board. You may also use this presentation to address these patient myths through education.
- If you are a patient, we hope that these facts help you make informed decisions about your health. You can also be a patient leader by educating other patients on the facts, especially when you hear these myths from your peers.

Treatment Options Overview



Treatment Options Overview

In-center Dialysis

Home Hemodialysis (HHD)

- Conventional
- Short daily
- Nocturnal

Peritoneal Dialysis (PD)

- CAPD – Continuous Ambulatory Peritoneal Dialysis
- CCPD – Continuous Cycling Peritoneal Dialysis

Transplant

No Dialysis

Myth vs. Reality – Home Dialysis

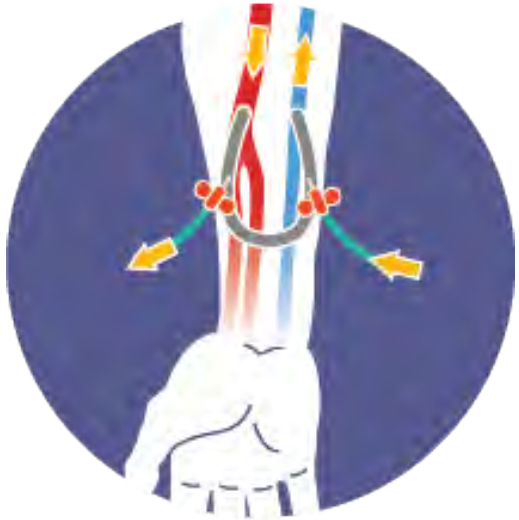
HHD Myth vs. Reality

Myth

A kidney patient can’t do home hemodialysis if they are afraid to insert their own needles.

Reality

Many patients have learned how to self-cannulate (insert their own needles) both for in-center and home dialysis. It can preserve the fistula, hurt less, and result in fewer complications.



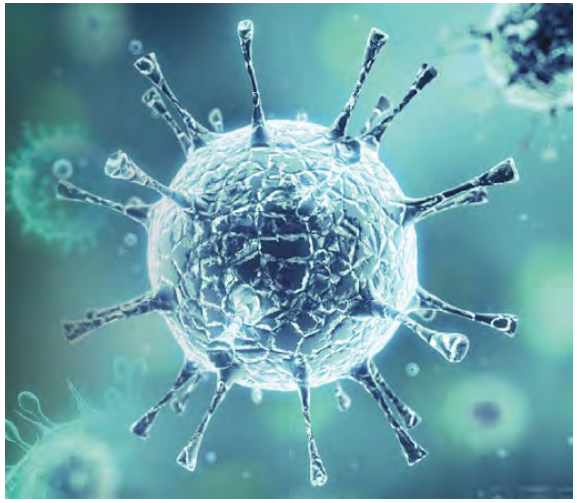
PD Myth vs. Reality

Myth

A kidney patient shouldn’t consider PD as an option because they will get an infection!

Reality

Peritonitis (an infection of the abdomen) can be prevented. It rarely occurs in good peritoneal dialysis (PD) clinics (about once every seven years).



HHD Myth vs. Reality

Myth

A home patient won't have any experts in the home to help them out.

Reality

The patient and/or their care partner will learn to be an expert, and the facility will provide 24/7 phone support. Help will always be nearby.

PD Myth vs. Reality

Myth

If a person is overweight, they can't do PD.

Reality

A catheter placed differently into the abdominal cavity may be a better option. PD can still be done.

HHD Myth vs. Reality

Myth

Home HD is a huge burden for a care partner.

Reality

It is best if the patient performs as much of their treatments as possible. Some people perform home HD without a care partner.

PD Myth vs. Reality

Myth

A kidney patient needs to have some kidney function in order to do PD.

Reality

Kidney function will always be checked, but PD can be done without any kidney function.

HHD Myth vs. Reality

Myth

A person could bleed to death very quickly at home while receiving dialysis.

Reality

No one has ever bled to death on home hemodialysis. Machine alarms alert you to the detection of just one drop of blood out of place. You will have time to react and fix the problem.

HHD Myth vs. Reality

Myth

If a person decides to do HHD, they must follow the same scheduled days of the week.

Reality

Many different schedules are available and can be arranged at home. There is short daily and nocturnal dialysis if you're interested in dialyzing while you sleep. The purpose of home dialysis is to set your own schedule.

General Information - Myth vs. Reality

Myth

Home dialysis, will cost more than at the dialysis unit.

Reality

No, not at all. Both Medicare and private insurance cover the cost of home dialysis.

General Information - Myth vs. Reality

Myth

A kidney patient will have to get rid of their pets to do dialysis at home.

Reality

Lots of people dialyze at home and still have pets. Clean well and ensure your pets stay out of the room when you connect or disconnect.

General Information - Myth vs. Reality

Myth

When a person dialyzes at home, they can eat and drink whatever they want.

Reality

Dietary and fluid intake limitations remain in place, but you may have a bit more flexibility with your limits and choices. Always check with your medical team when changing your renal diet.

General Information - Myth vs. Reality

Myth

A lot of space is needed in a person's home to do HHD or PD.

Reality

Home dialysis will require some space for supplies, but many people who live in efficiency apartments, mobile homes, and other small spaces find a way to make PD work.

General Information - Myth vs. Reality

Myth

If a person does dialysis at home, they won't be able to change dialysis types or be a candidate for transplant.

Reality

Not at all. You can always switch to another home modality or decide you'd like to go to in-center hemodialysis. Also, doing home dialysis does not make you less likely to receive a transplant.

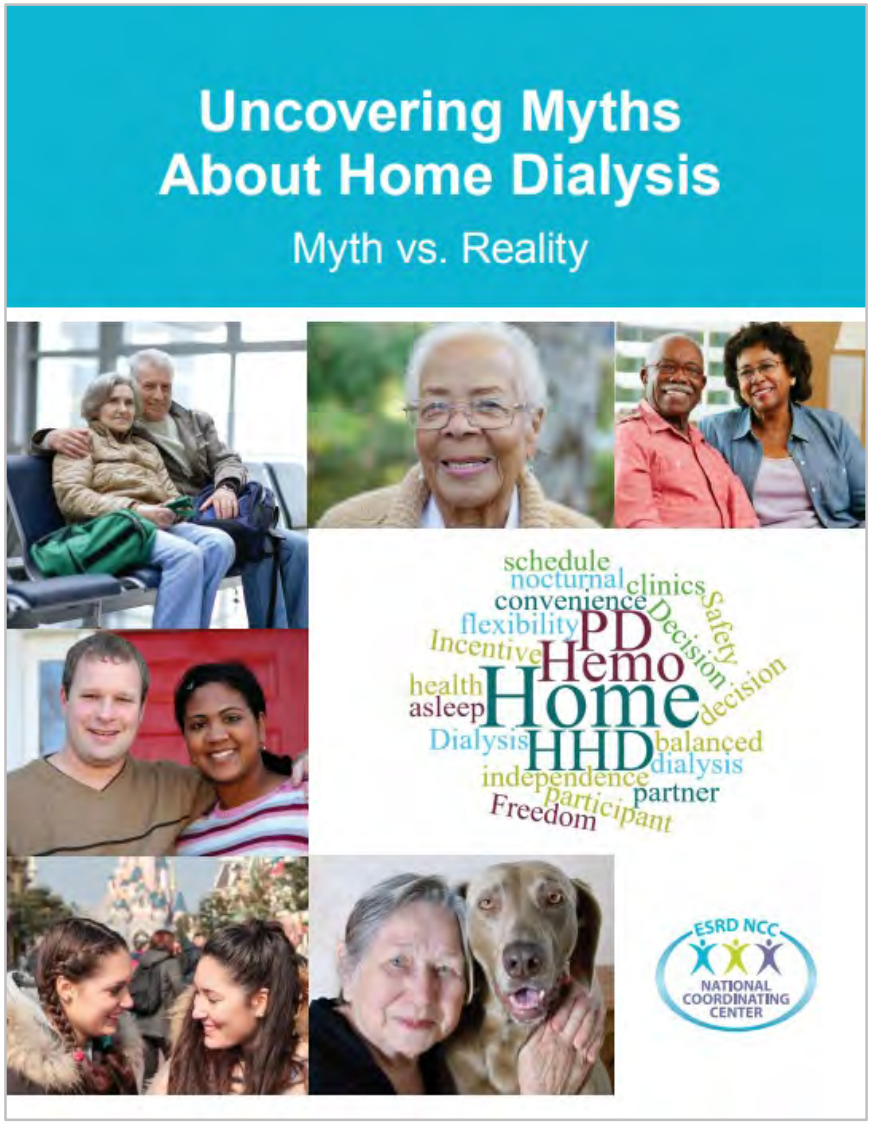
Home Dialysis Considerations

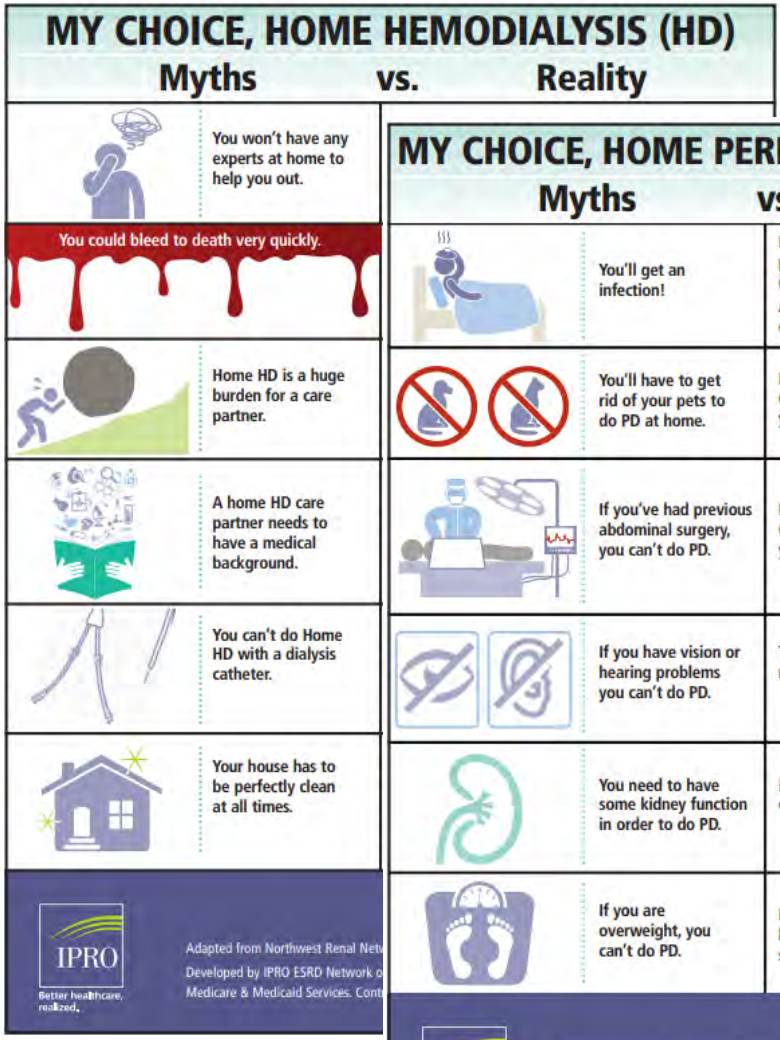
- More flexibility in dialysis and daily life schedules
- More normal diet with less restrictions
- May be able to reduce medications
- Less recovery time after treatment
- Reduced transportation hassles getting to and from the clinic
- Ability to travel more (depending on your capability with bringing the machine and supplies)
- More energy, both mentally and physically
- Better control of blood pressure
- Less stress on the heart

What type of support would be provided by the dialysis facility?

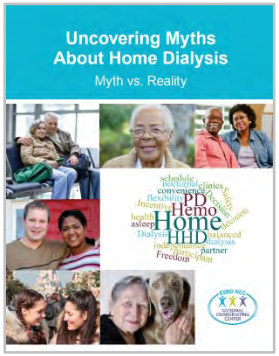
- Dialysis providers are required to educate about home dialysis treatment options and assess patient interest.
- The healthcare team can help in referring a patient to a home program.
- Home nurse will provide one on one training until a person is comfortable with dialyzing at home.
- A home nurse will assist in organizing your home with supplies needed for dialysis.
- A kidney patient will still have visits to the dialysis unit for monthly labs and evaluations.
- Remember, the dialysis unit staff will be available to you 24/7 either in the facility or by phone.

Myth vs. Reality Resources

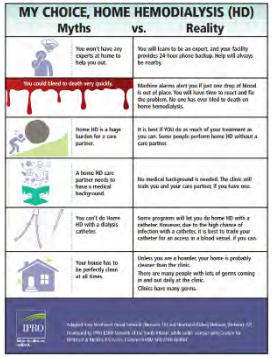




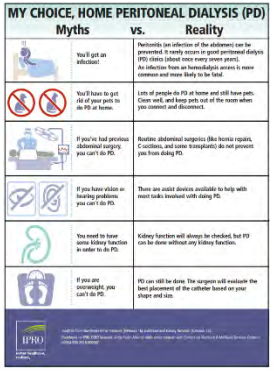
Myth vs. Reality Resource Links



https://network6.esrd.ipro.org/wp-content/uploads/sites/4/2016/01/Uncovering-Myths-About-Home-Dialysis.pdf



https://network6.esrd.ipro.org/wp-content/uploads/sites/4/2016/01/NW6-HomeTherapies-HD-Myths_v1.pdf



https://network6.esrd.ipro.org/wp-content/uploads/sites/4/2016/01/NW6-HomeTherapies-PD-Myths_v1.pdf

Myth and Reality – Kidney Transplant

Transplant Myth vs. Reality

Myth

A person receiving dialysis who would like to receive a living donor kidney transplant must have a **blood-related family member** who is willing to donate a kidney to them.

Reality

A donor can be a family member, friend or stranger as long as they are a compatible match for the recipient.

Transplant Myth vs. Reality

Myth

Kidney transplants can only be done if the recipient is under **70 years old**.

Reality

Many transplant centers in the nation do not have an age cut off, but rather assess the overall health status of the person needing a kidney transplant.

Transplant Myth vs. Reality

Myth

A transplanted kidney **will not last a long time**.

Reality

The average life of a kidney transplant depends on the donor type. Deceased kidneys last about 15 years; while living donor kidneys last about 15-20 years on average. Although kidney transplantation is not a cure, it can mean many years of freedom from dialysis treatments.

Transplant Myth vs. Reality

Myth

A person interested in a kidney transplant needs **private insurance** to pay for the procedure and anti-rejection medications.

Reality

A private health insurance is not required to receive a kidney transplant. In fact, Medicare covers kidney transplant costs for the recipient (and medical costs for a living donor, if involved).

Transplant Myth vs. Reality

Myth

A person **needs to be on dialysis** to be referred for a kidney transplant.

Reality

Pre-emptive transplant can be offered to people diagnosed with Chronic Kidney Disease (CKD) and GFR less than 20 even before starting dialysis. A referral can be made once the GFR reaches 30.
Some people never undergo dialysis treatments before getting their kidney transplant.

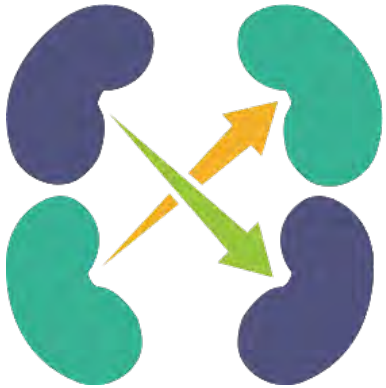
Transplant Myth vs. Reality

Myth

If a living donor is **not a direct match**, then the recipient is out of options to receive a living donor kidney transplant.

Reality

If a living donor is not a direct match to the recipient, then both parties can enter a **pair exchange program** (also known as a kidney swap).



Transplant Myth vs. Reality

Myth

Kidney transplant as a treatment option, is only a choice for the **wealthy.**

Reality

Kidney transplants are available to any eligible patient regardless of financial or social status. Transplant centers have financial coordinators that will evaluate the patient's situation to assure that can afford the costs related to the work-up process, surgery and care after the transplant, such as medications.

Transplant Myth vs. Reality

Myth

Kidney transplants are offered mostly to **Caucasian** kidney patients.

Reality

The Kidney Allocation System (KAS) makes the distribution of organs a fair and equitable process that does not discriminate against race or ethnicity.

Transplant Myth vs. Reality

Myth

If a person receives a kidney from a **Hepatitis C** positive donor they would develop the disease, which will lead to liver failure.

Reality

Some transplant centers have a program that offers the option to transplant a Hepatitis C positive kidney. After transplantation, the recipient is treated with antiviral medications to treat and cure the Hepatitis C.

Transplant Myth vs. Reality

Myth

A person with kidney failure can be referred to a transplant center only when they have **been on dialysis for at least a year**.

Reality

Although the time on dialysis is considered when allocating an available kidney from a donor, referral to the transplant center can be done at any time. No specific amount of time on dialysis is needed to start the process!

Transplant Myth vs. Reality

Myth

After a kidney transplant, all kidney **medications will stop**.

Reality

Although some medications related to dialysis can be discontinued, patients must take a daily anti-rejection medication to prevent the body from attacking or rejecting the transplanted kidney.

Transplant Myth vs. Reality

Myth

If a transplant center determines a patient is not eligible for a transplant, this means that a person will **never** be able to receive a kidney transplant.

Reality

A dialysis patient who has been determined as ineligible for a kidney transplant, can be **referred and evaluated** at another transplant center that has different criteria and/or try again at a later time when the patient meets the criteria at the original transplant center where he/she was not eligible.

Transplant Myth vs. Reality

Myth

The **first visit** to the transplant center, means that a patient has been added to the transplant waitlist and is now waiting for a kidney transplant.

Reality

On the first visit to the transplant center, a patient receives general education and may begin the assessment process with the healthcare team.
Once the transplant center has determined the patient meets their criteria, then a patient would be added to the transplant waitlist. Once a kidney becomes available that matches the patient, they will be called to get a kidney transplanted through surgery.

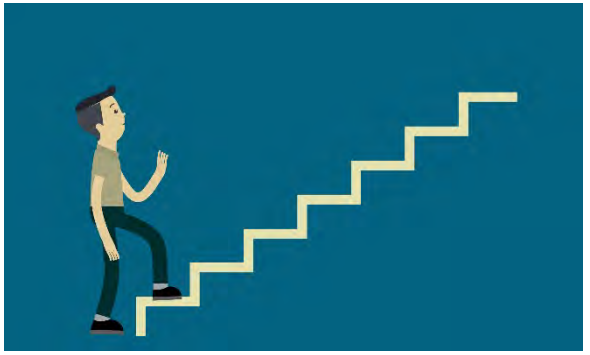
Transplant Myth vs. Reality

Myth

A patient must be referred to a transplant center by their kidney doctor or healthcare professional only.

Reality

Many transplant centers will accept self-referrals, meaning that the patient can refer themselves for a transplant center evaluation.



Transplant Myth vs. Reality

Myth

Being multi-listed with more than one transplant center is duplication of efforts.

Reality

When patients are multi-listed with two or more transplant centers located in different Donor Service Areas, the chances of receiving a kidney transplant sooner increases.

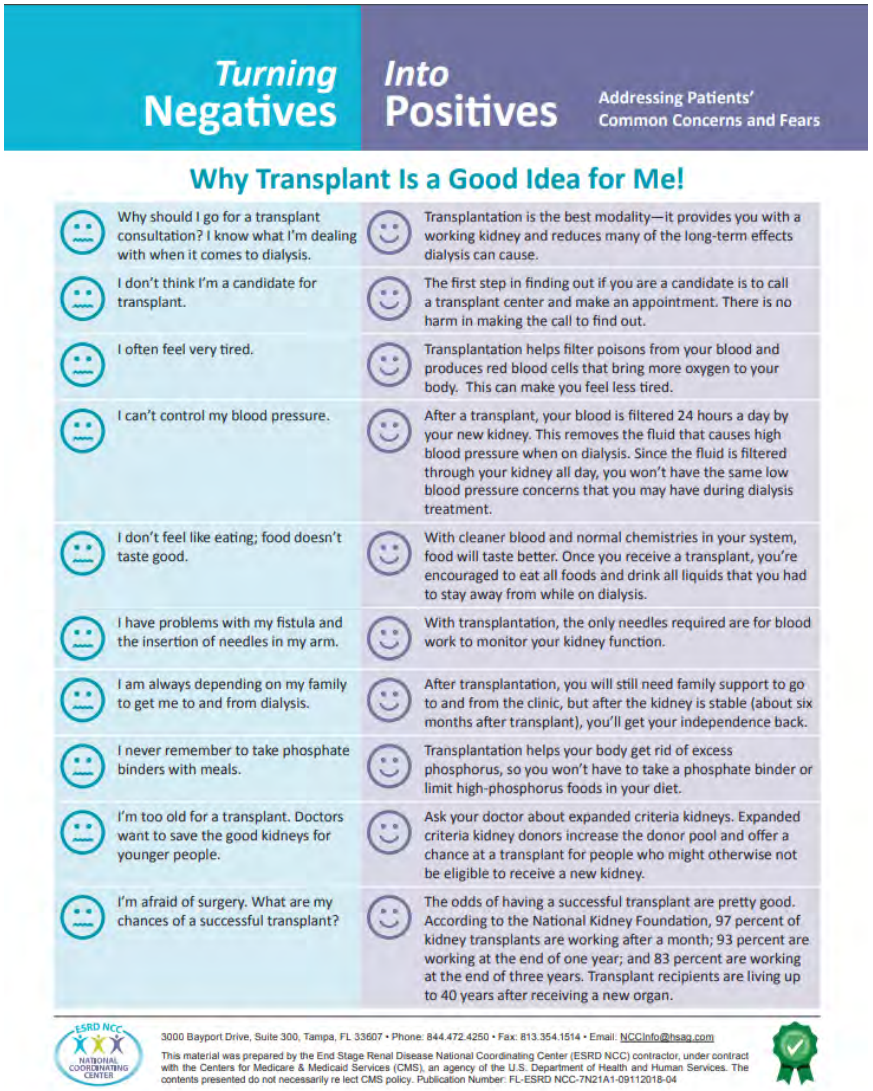
Transplant Considerations

- More flexibility in life and freedom from dialysis treatments
- Reduced transportation challenges getting to and from a clinic
- Flexibilities of going back to work or school
- Ability to travel with less hassle
- Less dietary restrictions, if any
- The new kidney works 24/7 cleaning your blood
- More energy, both mentally and physically
- It’s considered the best treatment option for both clinical and quality of life outcomes for kidney patients

What type of support would be provided by my dialysis facility?

- Dialysis providers must **educate** about kidney transplant as a treatment option and assess patient interest.
- The healthcare team can help in **referring** a patient to the transplant center
- The healthcare team might assist providing required **paperwork** such as H&P, insurance, 2744 and other forms
- The healthcare team can assist in reminding of upcoming **appointments** to the transplant center and/or related tests or procedures
- The Social Worker might assist in coordinating **transportation** for such appointments
- **Communication** between dialysis providers, transplant center and patient are crucial during this process

Turning Negatives into Positives



Turning Negatives Into Positives

Addressing Patients' Common Concerns and Fears

Why Transplant Is a Good Idea for Me!

Why should I go for a transplant consultation? I know what I'm dealing with when it comes to dialysis.	Transplantation is the best modality—it provides you with a working kidney and reduces many of the long-term effects dialysis can cause.
I don't think I'm a candidate for transplant.	The first step in finding out if you are a candidate is to call a transplant center and make an appointment. There is no harm in making the call to find out.
I often feel very tired.	Transplantation helps filter poisons from your blood and produces red blood cells that bring more oxygen to your body. This can make you feel less tired.
I can't control my blood pressure.	After a transplant, your blood is filtered 24 hours a day by your new kidney. This removes the fluid that causes high blood pressure when on dialysis. Since the fluid is filtered through your kidney all day, you won't have the same low blood pressure concerns that you may have during dialysis treatment.
I don't feel like eating; food doesn't taste good.	With cleaner blood and normal chemistries in your system, food will taste better. Once you receive a transplant, you're encouraged to eat all foods and drink all liquids that you had to stay away from while on dialysis.
I have problems with my fistula and the insertion of needles in my arm.	With transplantation, the only needles required are for blood work to monitor your kidney function.
I am always depending on my family to get me to and from dialysis.	After transplantation, you will still need family support to go to and from the clinic, but after the kidney is stable (about six months after transplant), you'll get your independence back.
I never remember to take phosphate binders with meals.	Transplantation helps your body get rid of excess phosphorus, so you won't have to take a phosphate binder or limit high-phosphorus foods in your diet.
I'm too old for a transplant. Doctors want to save the good kidneys for younger people.	Ask your doctor about expanded criteria kidneys. Expanded criteria kidney donors increase the donor pool and offer a chance at a transplant for people who might otherwise not be eligible to receive a new kidney.
I'm afraid of surgery. What are my chances of a successful transplant?	The odds of having a successful transplant are pretty good. According to the National Kidney Foundation, 97 percent of kidney transplants are working after a month; 93 percent are working at the end of one year; and 83 percent are working at the end of three years. Transplant recipients are living up to 40 years after receiving a new organ.

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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 presented do not necessarily re lect CMS policy. Publication Number: FL-ESRD NCC-7N21A1-09112018-04

- Address negative misconceptions with positive reinforcements about transplant
- Negative ideas about transplant can develop myths or false statements
- Facts can be presented in a positive light that motivate kidney patients to pursue a kidney transplant

https://www.esrdncc.org/globalassets/negpostransplantflyerfinal508.pdf

Treatment Options
Additional Resources

- Home Dialysis Central: https://homedialysis.org/home-dialysis-basics
- Home Dialyzors United: https://www.homedialyzorsunited.org/
- Explore Transplant: https://exploretransplant.org/
- National Kidney Foundation: https://www.kidney.org/treatment-support
- My Life, My Dialysis Choice: https://mydialysischoice.org/
- AAKP: https://aakp.org/center-for-patient-research-and-education/dialysis-education/
- Life Options: https://lifeoptions.org/living-with-kidney-failure/options-for-dialysis/

Thank You!

For more information:

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