

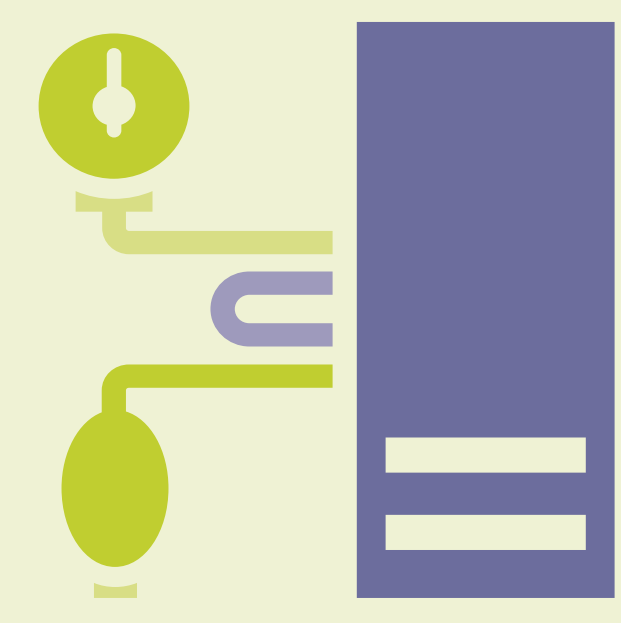
Patient Resources: A Journey for Creating Materials by Patients for Patients




Overview

The End Stage Renal Disease National Coordinating Center (ESRD NCC) National Patient and Family Engagement Learning and Action Network (NPFE-LAN) brings patients and families together to offer peer support and create resources that help patients understand their care options to make informed healthcare decisions and improve their health outcomes.

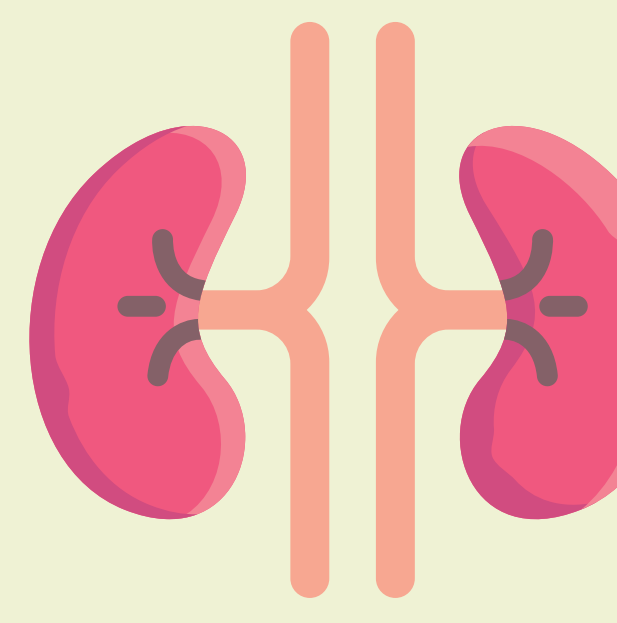
Who’s Involved?




50
In-Center Dialysis Patients




18
Home Dialysis Patients



36
Kidney Transplant Recipients




10
Family Members



CMS
Office of Minority Health

Materials Created by Patients for Patients

- Caring for Your Mind and Body
- How Might I Shorten My Time on the Kidney Transplant Waitlist?
- Where Should You Go for Medical Care?
- Understanding Home Hemodialysis as a Treatment Option
- Understanding Peritoneal Dialysis (PD) as a Treatment Option
- What You Need to Know About the Flu Vaccine



Caring for Your Mind and Body


Did you know, our mental health is always changing. We can feel strong one day and stressed the next. It's normal to have ups and downs, especially when you have kidney failure. But self-care and social support can help us get through the rough patches. Complete the questions below to consider if you need mental health support.

What are some words to describe how you feel?

Circle the number that corresponds to the picture that best describes how you feel.

What are some things that cause stress in your life? How do you deal with them?

When was the last time you were angry? What made you angry?



How Might I Shorten My Time on the Kidney Transplant Waitlist?

Did you know that you have options for shortening your time on dialysis and receiving a kidney transplant? In the United States, the average time on the transplant waitlist is four years according to the United Network for Organ Sharing (UNOS). Some people have a shorter time, and some people have a longer wait. This handout has tips that could make your time on the waitlist shorter.


Expanded Criteria Donor (ECD) kidneys come from donors over 60 years of age. ECD kidneys can also come from donors in their 50s with certain risk factors like high blood pressure, stroke, or reduced kidney function at the time of death.

On average ECD kidneys do not last as long as standard kidneys.

Wait 1-15 years for an ECD kidney? You have a lot of available kidneys.

Are you registering at two or more places? Register at a 1 to your home. But did you know you can register at another city or state? This may increase your size of receiving an organ offer.

Are you considering the treatment of chronic kidney disease? Your healthcare team about all your options.




Where Should You Go for Medical Care?

When you are sick or injured, knowing where to go to get good care can save you valuable time and frustration. Your first thought may be to call 911 or go to your local hospital's emergency room (ER). But the ER may not be the best place to be treated for your injury or illness. When your injury or illness isn't life threatening, the ER is an expensive, time-consuming attempt for help. There are other options that can be faster and less expensive.

Using the chart below, work with your healthcare team to identify what conditions you should see a doctor or nurse, or visit a clinic or urgent care facility, or the hospital ER.

What's best for you.	Kidney Doctor or Nurse	Clinic or Urgent Care Facility	Hospital ER	Notes
1				
2				
3				
4				



Home Hemodialysis May Be the Best Option for You

A resource focused on helping you understand the dialysis treatment option that may be best for you now or in the future.

Question: Do I have to follow the same dialysis scheduled days of the week if I choose home hemodialysis?

Answer: Many different schedules are available and can be arranged to fit your life. You can choose to do dialysis at home or in a facility. You can choose to do dialysis three times a week or four times a week. You can choose to do dialysis at home or in a facility. You can choose to do dialysis three times a week or four times a week.

Question: I have had surgery in my stomach area. Can I still do Peritoneal Dialysis (PD)?

Reality: You can still do PD if you've had abdominal surgeries like hernia repair, C-section, and some transplants. Your kidney doctor (nephrologist) and surgeon will let you know if PD is an option for you.

Question: What if I have problems with my vision or hearing? Can I still do PD?


Reality: There are aids, such as a hands-free magnifier with a battery-operated light or voice recorder to speak out instructions, available to help you with most tasks involved in doing PD.

Question: Do patients need to have a lot of space to do PD at home?

Reality: Patients do need some space for PD. A closet-sized space is typically needed for supplies.

Question: Can patients who are overweight perform PD?

Reality: While all PD involves having a special fluid in the abdomen, patients who are overweight should talk with their doctor about what is the best option for their circumstance.



Peritoneal Dialysis May Be the Best Option for You

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Get the Facts About the Flu Vaccine


A resource to help you understand the facts about the flu vaccine.

Myth	Fact
You can catch the flu from the vaccine.	The flu shot is made from a dead or inactivated virus that can't spread infection. It takes a week or two to get protection from the vaccine.
Getting the flu vaccine is all you need to do to protect yourself from the flu.	There are other steps to protect yourself during flu season: <ul style="list-style-type: none">• Avoid contact with people who have the flu.• Wash your hands frequently.• Consider taking medicine that fights off the flu if you were exposed to it before being vaccinated.
You don't need to get a flu shot every year.	The influenza virus changes (mutates) each year. So, getting vaccinated each year is important to make sure you have protection for the strains most likely to cause the flu.
Healthy people don't need to be vaccinated.	While it's especially important for people who have a chronic illness kidney disease to get the flu shot, anyone—even healthy folks—can benefit from being vaccinated.
The flu vaccine has many side effects.	The flu shot has one of the best safety records of any vaccine. The most common complaint is soreness and tenderness at the injection site.

The Centers for Disease Control and Prevention (CDC) recommends everyone 6 months and older in the United States should get the flu vaccine. According to the CDC, people with chronic kidney disease at any stage, people who have had a kidney transplant, and people who treat with dialysis are at increased risk of severe illness from flu.

www.health.hawaii.gov/diseases-and-conditions/cd-flu-myths

www.esrdncc.org/education/flu-vaccine-flu-myths



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