Step-by-Step Guide for Creating your ESKD Life Plan

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Welcome

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The End Stage Kidney Disease (ESKD) Life Plan is about making your healthcare goals, values and preferences known. It is important to plan ahead, and the best time to express yourself is now.

This step-by-step guide is designed to help you understand your options for taking care of your ESKD and think about what is most important to you. It includes explanations and thoughtful exercises that can help you make your Life Plan together with your care team in a way that feels right for you.

Let's get started!

Contents

Part 1: My healthcare goals, values, and preferences

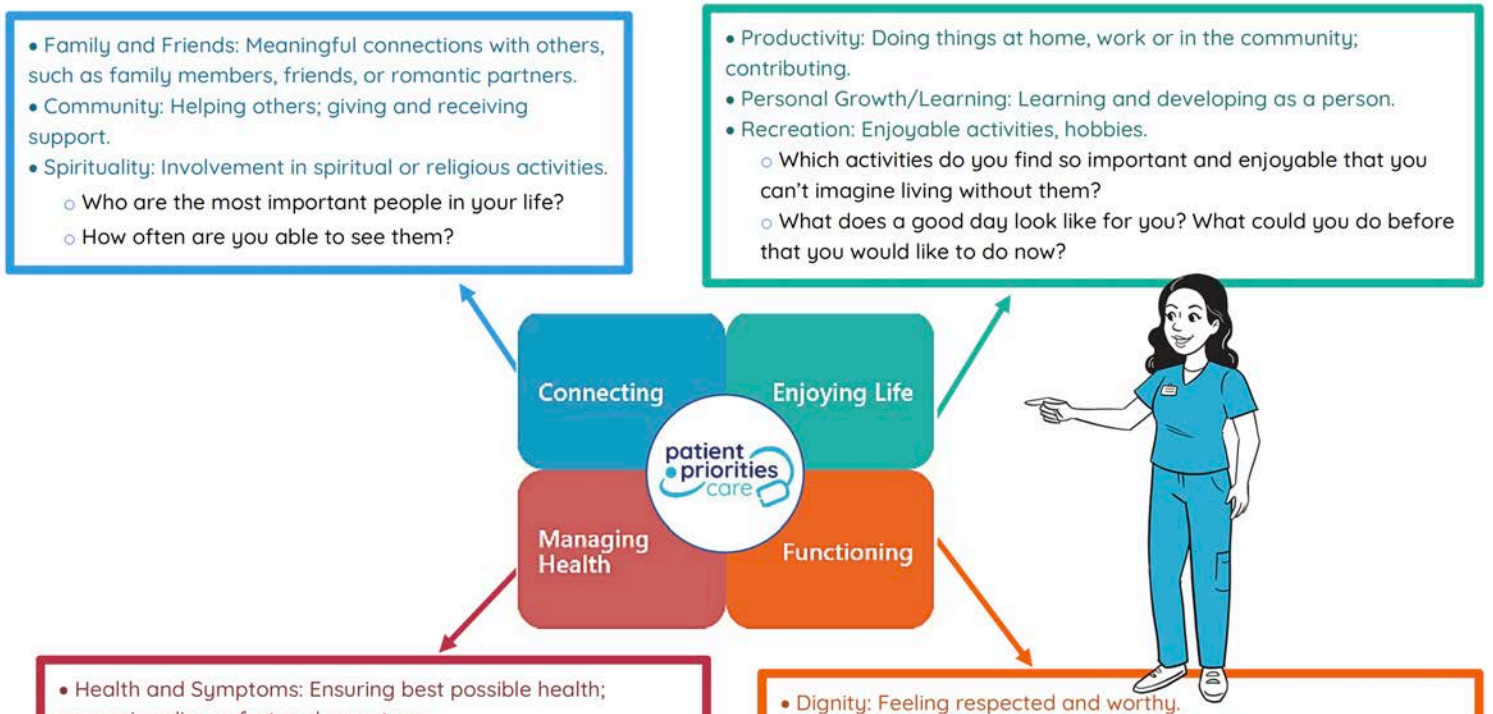
This section allows you to share what matters to you. This information will help your medical team better understand who you are and what is most important to you.

You can use these topics to help you fill out what is most important to you on the next page:

Values Conversation Starters

- Family and Friends: Meaningful connections with others, such as family members, friends, or romantic partners.
- Community: Helping others; giving and receiving support.
- Spirituality: Involvement in spiritual or religious activities.
  - Who are the most important people in your life?
  - How often are you able to see them?

- Productivity: Doing things at home, work or in the community; contributing.
- Personal Growth/Learning: Learning and developing as a person.
- Recreation: Enjoyable activities, hobbies.
  - Which activities do you find so important and enjoyable that you can't imagine living without them?
  - What does a good day look like for you? What could you do before that you would like to do now?



- Health and Symptoms: Ensuring best possible health; managing discomfort and symptoms.
- Quality of Life: Balancing the desire for maintaining how you feel today with the desire to live as long as possible.
  - What do you hope your health care can do for you?
  - In what ways do your health conditions and treatments limit your ability to do what matters?
  - What is more important to you - quality of life or living as long as possible?

- Dignity: Feeling respected and worthy.
- Independence: Managing self-care needs; living and moving independently and safely.
  - What kinds of actions are you able to do to take care of yourself? What are you not able to do to take care of yourself?
  - When taking care of yourself, what is most important to you now?
  - How do you feel about asking for or accepting help?

You can visit **MyHealthPriorities.org**, where an interactive online experience will walk you through the thought process.

When you have your priorities, print them out or take a picture. You can show them to your doctor on your next visit.

Most Important Health Goals

Health goals are specific and realistic activities or outcomes that show you are doing what matters most in your life. These health goals are what you want to achieve with your healthcare.

1. _____

2. _____

Care Preferences

Helpful care: Self-management tasks, clinical visits, tests, or procedures that you think are helping most with your health goals and you can do them without too much difficulty.

1. _____

2. _____

Burdensome care: Self-management tasks, clinical visits, tests, or procedures that you don't think are helping your goals and are burdensome or too difficult. You should talk with your doctor about whether these are helping your goals. If not, can you stop them or cut back? If they are helping, is there a way to make them less burdensome or less difficult?

1. _____

2. _____

Current Medications

Helpful: Medications you think are helping most with your health goals and you can take without too much difficulty.

1. _____

2. _____

Burdensome: Medications you don't think are helping your goals and are too burdensome. You should talk with your doctor about whether these are helping your goals. If not, can you stop or decrease them? If they are helping, is there a way to make them less burdensome?

1. _____

2. _____

What is the symptom that bothers you the MOST?

What is your MOST important health goal?

What ONE THING do you most want to focus on so that you can achieve your most important health goal more easily?

Part 2: Learning about choices for managing my kidney disease

Kidneys

What are kidneys?

- Kidneys are two organs in the abdomen (belly)
- There is one on each side of the abdomen
- They are each about the size of a fist

What does "renal" mean?

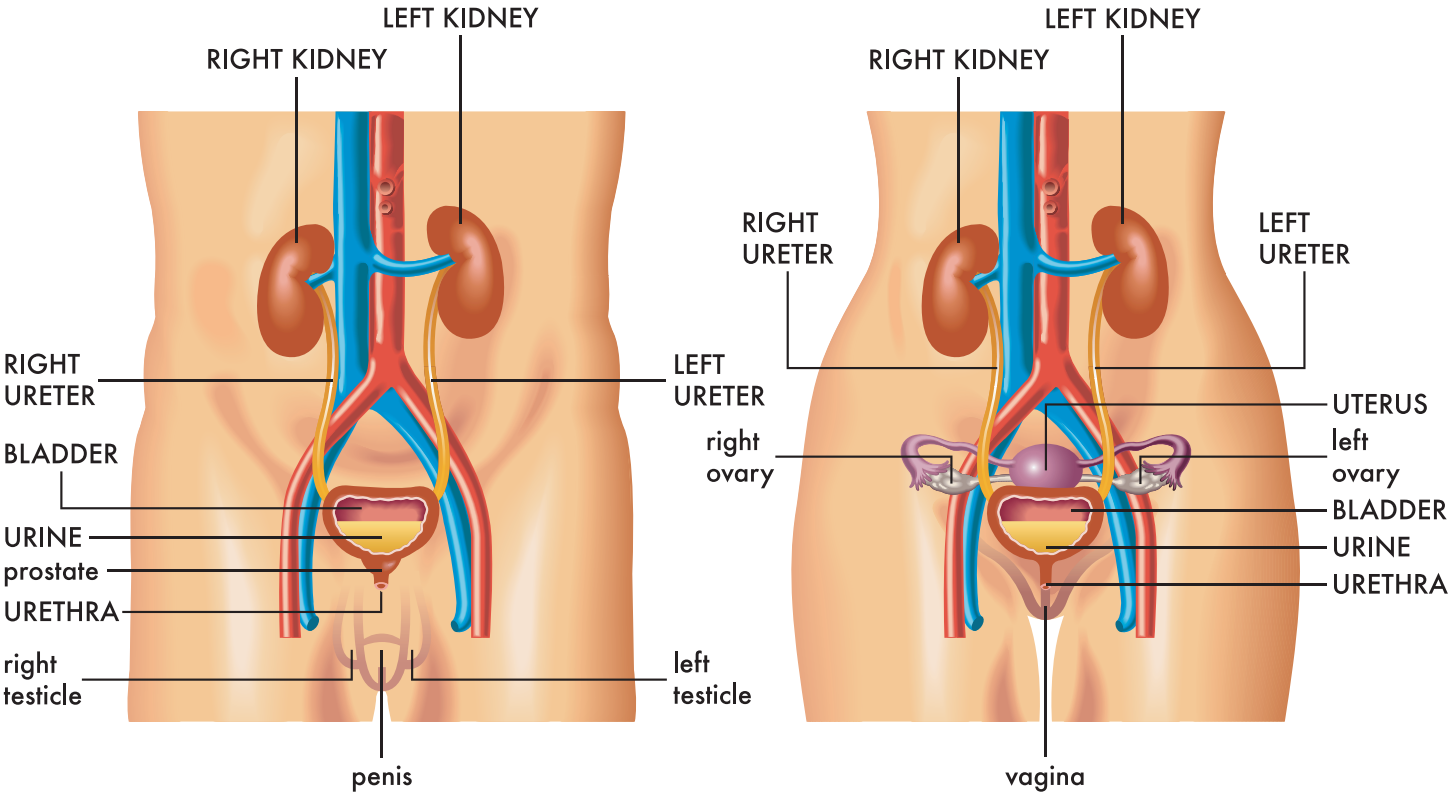
- The term "renal" refers to anything related to the kidneys

What do kidneys do?

- Kidneys clean the blood and remove extra fluid from the blood. The waste and extra fluid is removed from the body in the urine.
- Kidneys balance chemicals in the body
- Kidneys help control blood pressure and other functions such as making blood and keeping bones healthy

How do I know if my kidneys are doing their job well?

- Kidney function is measured through blood tests by measuring the creatinine (Cr)
- As kidney function gets lower and more abnormal, the creatinine increases
- See GFR (page 9)



Kidney Disease

What is kidney disease?

- Kidney disease refers to any decrease in kidney function. This means the kidneys are not doing their job as well.

What is the difference between acute kidney disease and chronic kidney disease?

- Acute kidney disease (or acute renal failure) means that there has been a sudden decrease in kidney function
- Chronic kidney disease (CKD) means that the kidney function is slowly decreasing. Most people with kidney disease have CKD.

What causes kidney disease?

- CKD is usually caused by other medical problems. The most common causes are high blood pressure and diabetes. It can also be caused by certain genetic conditions.
- Acute kidney disease can be caused by a sudden change in health. This may be an illness or injury that harms the kidneys.

What is GFR?

- GFR stands for glomerular filtration rate
- The GFR is calculated using a formula that includes the creatinine level, age, and sex
- As kidney function gets lower and more abnormal, the GFR decreases
- The GFR is used to categorize the severity of kidney disease

Can kidney disease be cured?

- Most CKD cannot be cured
- Many cases of acute kidney disease can be treated and sometimes cured

What can I do to keep my CKD from getting worse?

- Your doctor may recommend medications to protect your kidney function
- A low protein diet may help protect your kidneys
- Avoid medications that can hurt your kidneys
- Do not smoke tobacco
- Control the cause of the kidney disease, such as high blood pressure or diabetes

Kidney Failure

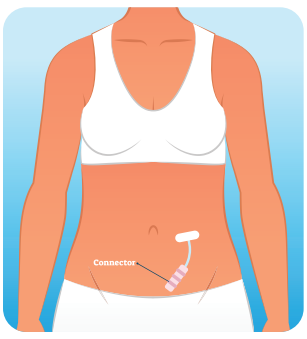
What is kidney failure?

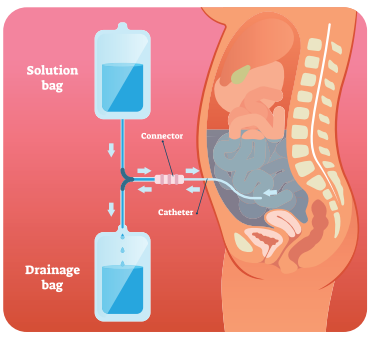
- Kidney failure is when both kidneys are not doing their job
- With kidney failure, the body fills up with extra fluid and wastes

What are my options if I have kidney failure?

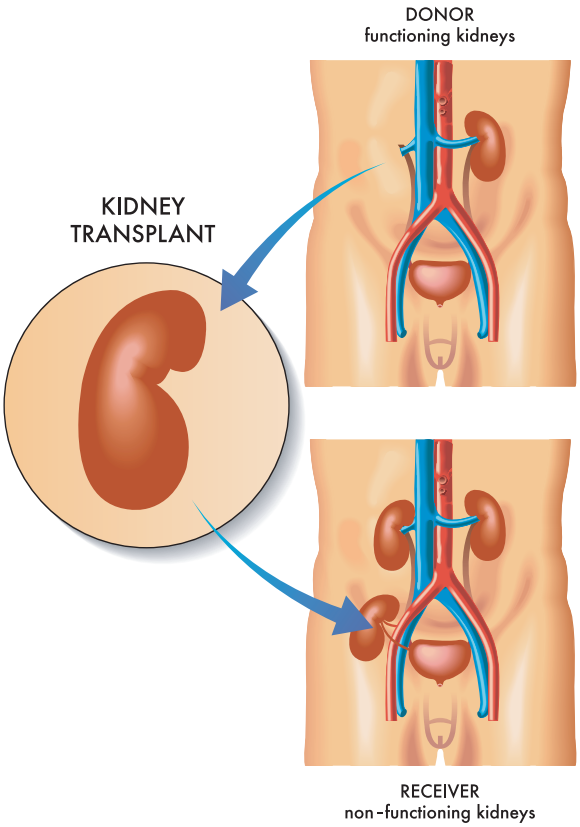
- Hemodialysis (HD)
  - Cleans the blood by using a machine
  - See page 18 for more information

- Peritoneal dialysis (PD)
  - Uses the natural lining inside the abdomen to filter out wastes and extra fluid
  - See page 14 for more information





- Kidney transplant
  - Takes a kidney from another person (donor) and puts it into the body of the person with kidney failure
  - See page 12 for more information



What are my options if I have kidney failure? (continued)

- Medical management without kidney replacement therapy
  - The doctor will prescribe medications that help control the extra fluid and waste
  - A lower protein diet can minimize waste products in the blood
  - Drinking and eating less liquid can minimize buildup of fluid in the blood
  - Over time, the kidney failure will get worse. Medications will not be able to control the fluid and the waste.
- Palliative care
  - No treatment
  - The patient is made as comfortable and free of pain as possible

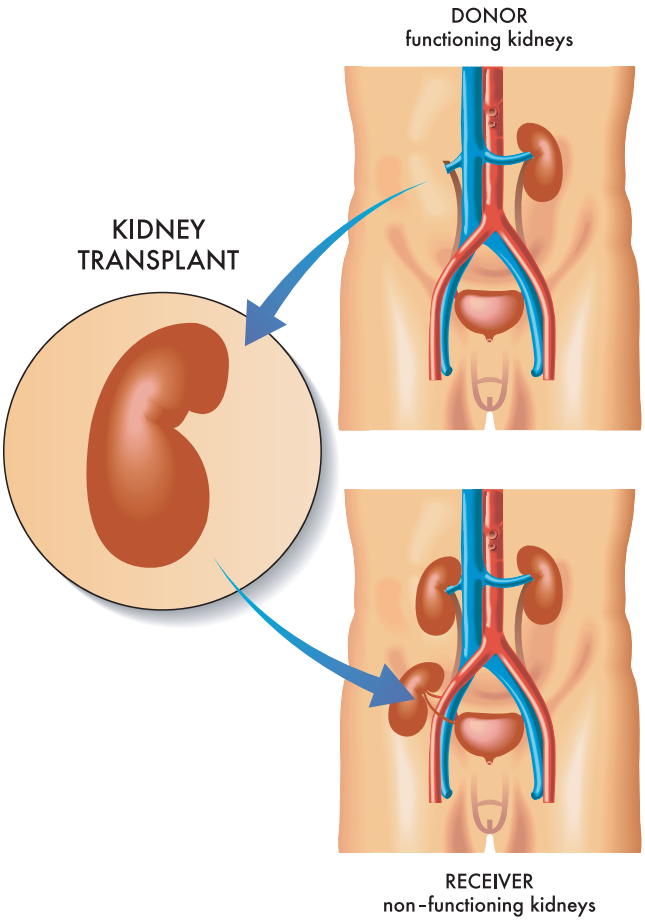
What will happen if I choose not to have any treatment for my kidney failure?

- Wastes and extra fluid build up in the body
- Eventually, the body will not be able to continue to function

Kidney Transplant

What is a kidney transplant?

- A functioning kidney from one person (donor) is given to a person with kidney failure (recipient)



Where does the donor kidney come from?

- The donor can be a living donor. A living-related donor is someone who is related to the recipient by blood. A living, non-related donor is someone who is not related by blood.
- The donor can be a deceased donor who agrees to donate their organs for transplant after they pass

Who can be a kidney transplant recipient?

- There are many criteria that a patient must meet to qualify as a kidney transplant candidate
- The transplant team determines whether kidney transplant is safe and beneficial for you
- The assessment includes blood tests, imaging scans and other tests
- The team will check for other serious medical conditions
- Kidney transplant recipients must accept the requirement to care for the kidney after transplant. This will include long-term medication to keep the transplant working.

What does getting a kidney transplant involve?

- A kidney transplant is a major operation that takes 3-4 hours to perform
- The donor kidney is placed in the transplant recipient through a cut in the patient's lower abdomen
- The donor kidney is connected to the recipient's blood vessels and urinary bladder
- Most kidney transplant recipients stay in the hospital 3-5 days after the operation. They are encouraged to walk the same day.

How long does it take to get a kidney transplant?

- First, the transplant team determines that the patient is a good candidate for a kidney transplant. Then, the patient is added to the national organ transplant list.
- The average wait time for a deceased donor kidney varies by region. For the most accurate estimate, ask your transplant center about their typical wait time.
- Patients who have living donors can sometimes get a kidney transplant sooner

How do I make sure my transplanted kidney stays healthy?

- Staying well hydrated by drinking plenty of water and fluids every day
- Avoid medications and supplements that might hurt the transplanted kidney
- Importantly, transplant recipients must take a number of medications multiple times a day, every day

Does a kidney transplant last for the rest of the recipient's life?

- On average, kidney transplants last between 10-12 years
- Sometimes, the transplant recipient's body will try to reject (attack) the transplanted kidney. This is because the body sees it as a foreign object. The medicines are supposed to help prevent this. If rejection happens, the transplanted kidney could last much less than 10-12 years.

To hear about what patients have experienced with kidney transplant, visit:

Jonathan and Melissa's Story: youtu.be/qVde-_Ms6ws

Philip's Story: youtu.be/ujyqobjx0yU

Nichole's Story: youtu.be/3-p2JRIqfFA

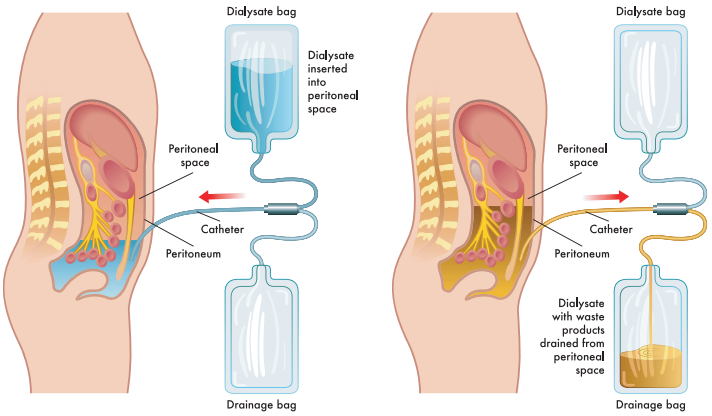
Peritoneal Dialysis (also called PD)

What is peritoneal dialysis?

- Peritoneal dialysis (PD) uses the lining of your abdomen (called the peritoneum) to filter out wastes and extra fluid

How does PD work?

- PD is performed through a plastic tube called the PD catheter. One end is in the abdomen, and the other end is outside the body.
- The tube is used to put clean fluid (called dialysate) into your abdomen. The fluid flows through the abdominal cavity and pulls out toxins.
- After a period of time (called dwell time), the fluid is drained from the abdomen through the tube and discarded
- Each time fluid is put in and taken out of your abdomen is called an “exchange”



Who can have PD?

- The ideal candidate for PD is someone who has not had abdominal surgery before
- Prior surgery can lead to scar tissue in the abdomen. This can make PD less effective. The scar tissue can also make the operation to place the PD catheter risky.

Where would I do PD?

- PD is done in your own home

When would I do PD?

- There are two options for timing of the PD. One is called continuous ambulatory PD (CAPD). The other is called continuous cycling PD (CCPD).
- In CAPD, the patient connects the PD catheter to tubing. The patient puts the fluid in and drains the fluid out manually. Usually, 3-5 exchanges are done per day. Each exchange takes about 30-45 minutes.
- In CCPD, the patient connects the PD catheter to a machine. The machine does the fluid exchanges while the patient is sleeping.

What would I need to do at home to make PD safe?

- The area where the PD catheter comes out of the skin should be kept clean all the time to prevent infection
- The boxes of supplies will need a space to be kept
- The PD should be performed in a separate room that is kept clean by vacuuming and dusting. Pets should not be allowed in the room. The equipment used to perform the dialysis should be kept in this room and cleaned regularly.