



Name \_\_\_\_\_

Study ID \_\_\_\_\_

Below is a guide that you can use to help you remember when you should be completing each of your sessions, and when to expect a phone call from someone on the study team!

Session 1 to be completed the week of:

\_\_\_\_\_

Session 2\* to be completed the week of:

\_\_\_\_\_

Session 3 to be completed the week of:

\_\_\_\_\_

Session 4\* to be completed the week of:

\_\_\_\_\_

Session 5 to be completed the week of:

\_\_\_\_\_

Session 6\* to be completed the week of:

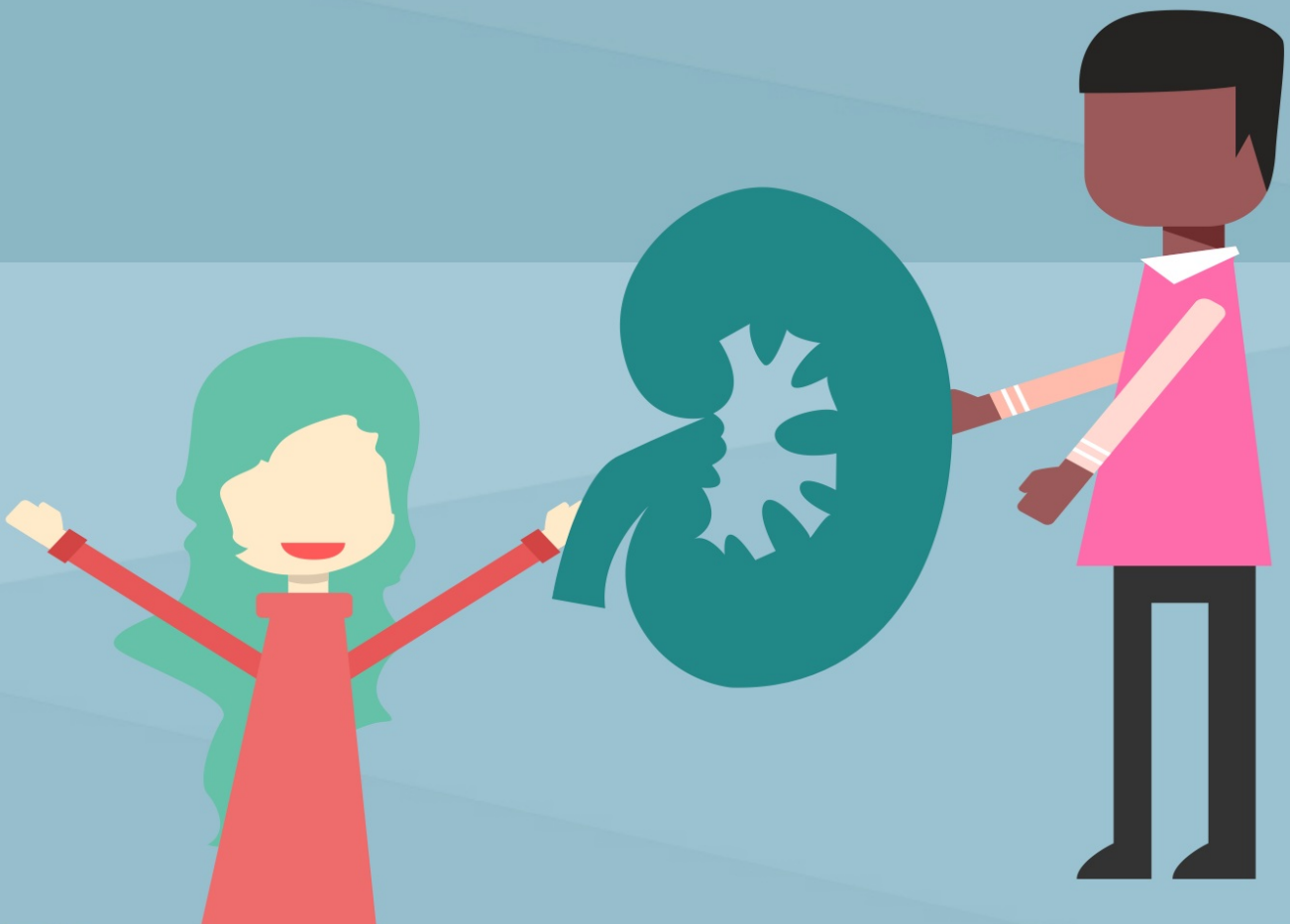
\_\_\_\_\_

\* You will receive a phone call from someone on the study team after you have completed session 2, again after session 4 and a final phone call after the last session, session 6! When they call, remember that they will ask you to grab this workbook, so make sure you always know where it is! Once you've had this phone call at each of these weeks, we will send you your gift card!

About 3 months after you finish your last session, you will be asked to take a final round of surveys and answer some questions online. After this, you will be sent your final gift card worth \$20!

# SELF- MANAGEMENT

In this booklet, we will learn about chronic kidney disease and choices to help you live a healthy life.





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**GLOSSARY:** Bold words can be found here!

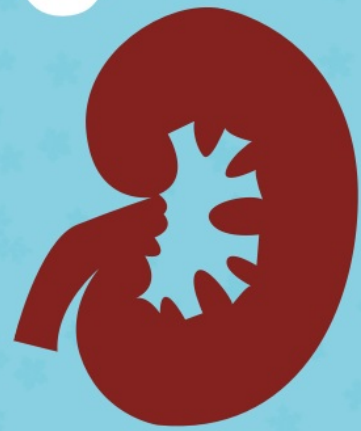
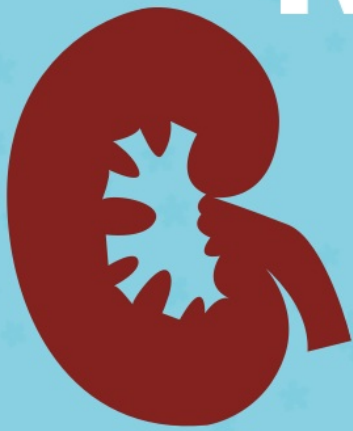
**APPENDIX:** Common medicines, Additional Resources



This booklet will provide a general overview of things that you can do to manage your kidney disease. If you have any questions or are unsure of what steps you should take to be your healthiest, talk to your doctor!



# INTRODUCTION TO THE KIDNEYS



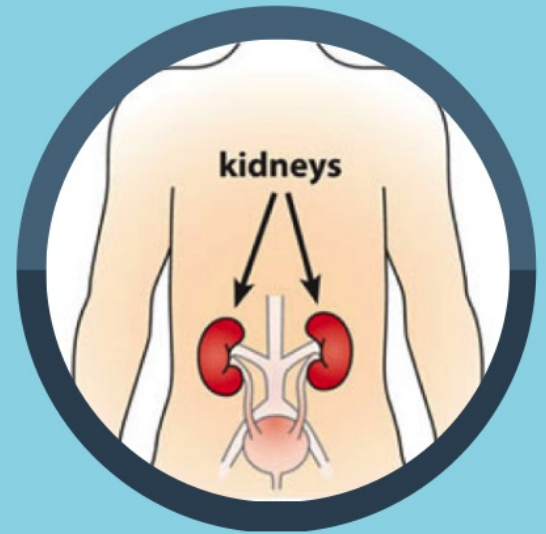
In this session, we will work to understand the anatomy, function, and role of the kidneys.



# What are the kidneys?

Week 1

- There are 2 kidneys
- There is one on either side of your back
- Each kidney is about the size of your fist



What does **RENAL** mean?

Something is related to the kidneys.

ex. renal failure is when the kidneys stop working

What is an **ARTERY** or a **VEIN**?

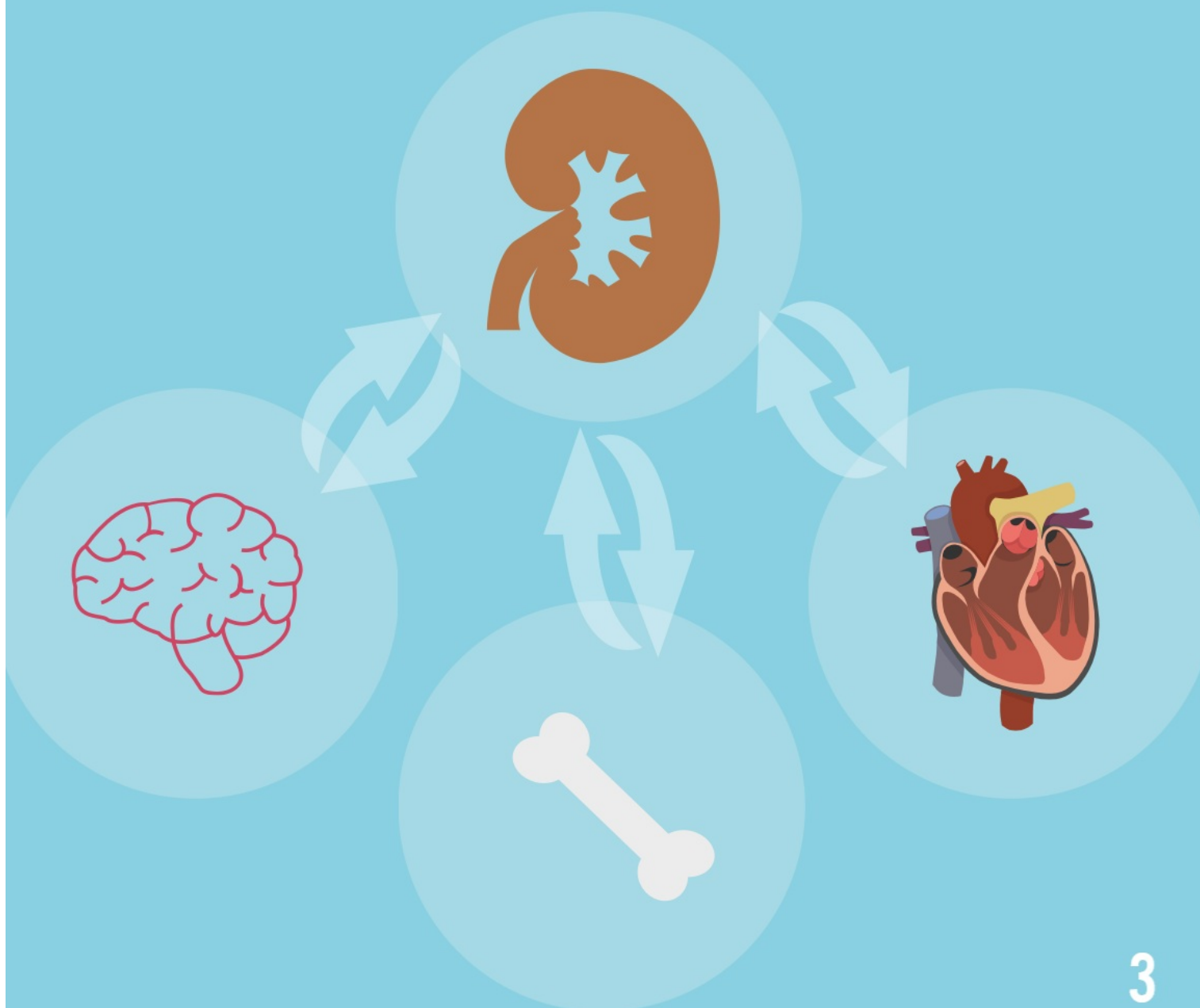
Your arteries and veins are like a highway for blood to move throughout your body



When a word is in **BIG** letters, you can check the glossary in the back of the book to see what it means!

The systems of your body are all connected! This means that different systems can send each other messages about what the body needs to do.

Your kidneys work with your brain, bones, heart, and rest of your body to make sure that your body gets everything that it needs for you to live a healthy life. If your kidneys are not working, they might not be able to send or receive messages from the rest of your body.





# All About the Kidneys

Week 1

## What the Kidneys Do:

**Filter  
your  
blood**

**Remove  
extra  
water to  
make  
urine**

**Make  
hormones**

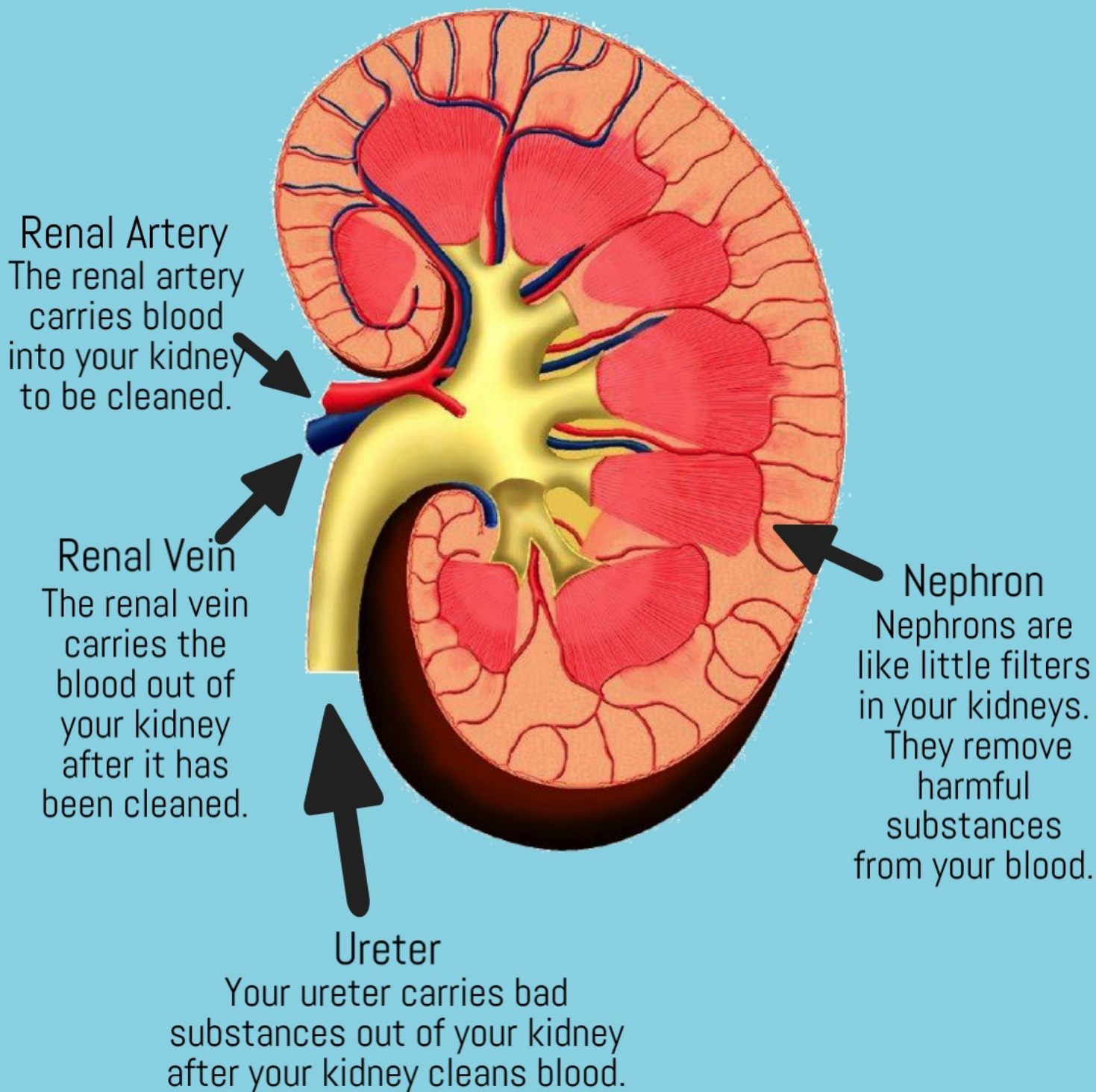
**Remove  
waste**

**Help control  
blood  
pressure**

Note: When the kidneys are damaged, wastes can build up in the body.

# A Closer Look at your Kidneys

Week 1



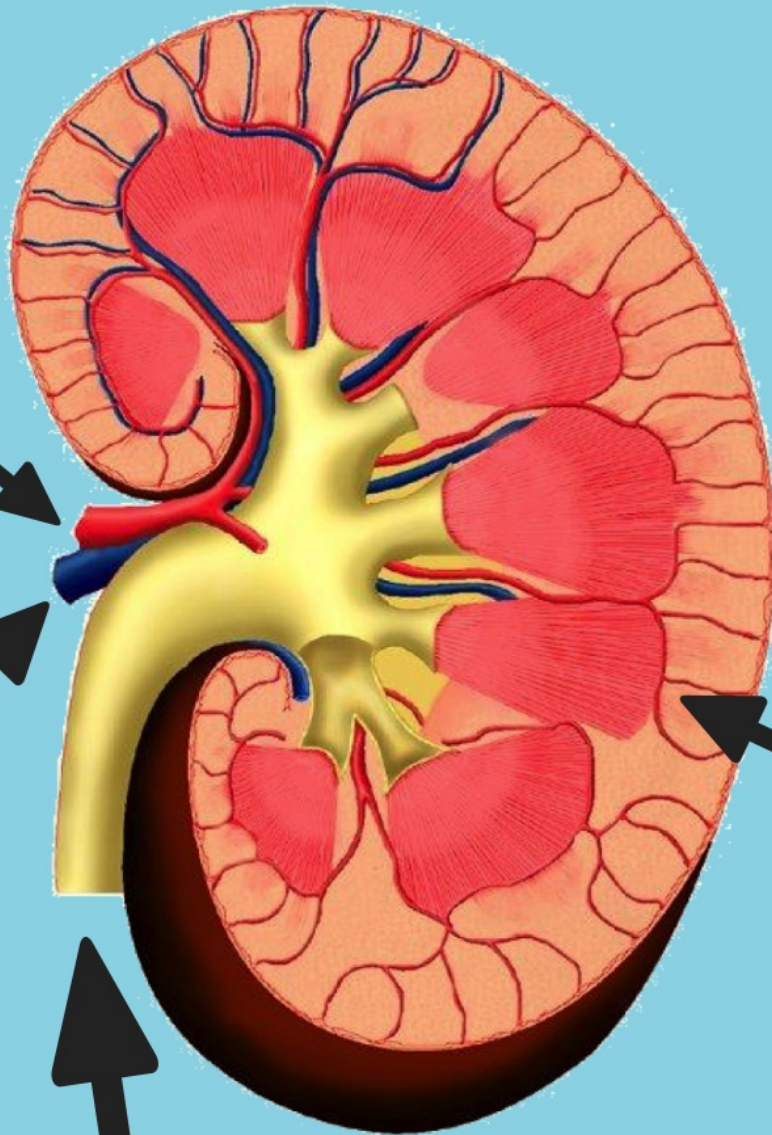


# Activity:

Answer these questions about the parts of the kidney.

1 \_\_\_\_\_ 3 \_\_\_\_\_

2 \_\_\_\_\_ 4 \_\_\_\_\_



1  
**Renal Artery**  
What does the renal artery carry into the kidney to be cleaned?

2  
**Renal Vein**  
Does the renal vein take clean blood into or out of the kidney?

3  
**Ureter**  
What does your ureter carry out of your kidney?

4  
**Nephron**  
What do the nephrons do?





# What do the kidneys do?

Week 1



Your kidneys are like a **laboratory**.

## They can...

1. Control Vitamin D for strong bones 
2. Tell your body to make red blood cells
3. Get rid of drugs/medicines 
4. Get rid of acid and fluid
5. Get rid of waste 
6. Make **HORMONES** to control blood pressure
7. Balance salt, **POTASSIUM**, and **PHOSPHORUS** 



# How much fluid do the kidneys handle?

Week 1

50 x



One gallon  
=  
one milk jug!

Your kidneys handle about 50 gallons of liquid every day!

The kidneys work really fast!



# Acid and Your Kidneys

Week 1

Kidneys control salt, potassium, phosphorus, and acid in your body...  
Everything you eat has these things!

When you eat, your body makes acid.

When your kidneys work, they filter out the acid and get rid of it through urine.

If your kidneys cannot get rid of acid, your body cannot grow as well as before.



If you have this problem, a daily shot of growth hormone can help you grow.

## DID YOU KNOW?

Your body makes less acid if you eat mostly vegetables. It makes more acid if you eat mostly meat!





# Kidney Connections

Week 1

If your kidneys are not working:



They cannot get rid of phosphorus and your bones can become weak.



Your **BLOOD PRESSURE** may change.  
If your blood pressure gets too high, your brain might not be able to work as well as before.



You may have a hard time learning because of chemical changes.

If you want more information, look for this logo

Advanced Material

# SUMMARY

Week 1

## Functions of the kidneys:

- Keep up with vitamin D for strong bones
- Tell your body to make red blood cells
- Get rid of drugs
- Cancel out acid and fluid
- Get rid of waste
- Make hormones to control blood pressure



# Check-In questions:

Week 1

1. Where are the kidneys located?

- a) on each side of your back
- b) on each side of your stomach
- c) in your bladder
- d) beside your heart

2. Which of the following is something that the kidney does?

- a) Gets rid of acid and fluid
- b) Gets rid of waste
- c) Makes hormones to control blood pressure
- d) all of the above

3. Which of the following do the kidneys NOT help control?

- a) salt
- b) sugar
- c) potassium
- d) phosphorus

4. How many gallons of fluid do the kidneys handle every day?

- a) 2
- b) 10
- c) 50
- d) 100

5. True or False: The kidneys help control your blood pressure.

- a) True
- b) False

## Kidney-Hormone Connection

Parathyroid Gland:

- Located in your neck
- Makes hormones that control growth of your bones

Acidosis:

- If your kidneys fail, they cannot get rid of acid.
- In time, you may have too much.

**ACIDOSIS** is the build up of too much acid in your body!

**Acidosis sends the wrong message to the parathyroid.**



**The parathyroid makes hormones that tell your bones not to grow.**

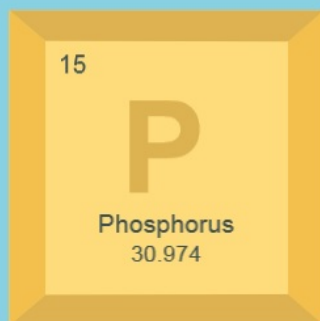


**Your bones may get thin, become weak, even break.**




## Kidney-Bone Connection

**If your kidneys fail, they cannot get rid of the phosphorus that you eat.**



Phosphorus is a mineral that keeps your bones strong!  
But too much phosphorus is bad!

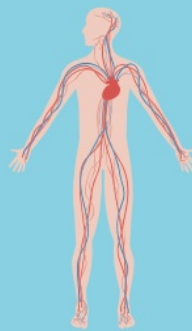
**High phosphorus** → **You may have pain in your bones or they may become weak or break.** 

If your kidneys fail, you will need to:

- 1) Change what you eat (less phosphorus) to have strong bones.
- 2) Take medicines that stick to the phosphorus in your intestines, before it gets into your blood!

## Kidney-Heart Connection

The kidneys also help control blood pressure.



**BLOOD PRESSURE:**  
How strong your heart beats to move blood through your body!

Two numbers are checked for your blood pressure:

1. Systolic pressure (bigger number) = how much pressure when your heart is squeezing the most.
2. Diastolic pressure (smaller number) = pressure when your heart rests between beats.

Normal blood pressure is about 120/80 for most people.



## Kidney-Heart Connection Continued

Why do you need a good blood pressure number?

1. To protect your heart and brain.
2. When your kidneys fail, your blood pressure may go up.
3. High blood pressure can lead to other health problems, like heart attacks and strokes that can hurt your brain.



Write down your blood pressure here! You can use this list to keep track of your blood pressure reading every time you go to the doctor.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

## Kidney- Bone Marrow Connection

**Kidneys make a hormone called erythropoietin (EPO).**



EPO tells your bone marrow to make new red blood cells.



Red blood cells help carry oxygen from the lungs to the rest of your body.



When your kidneys fail, they stop making EPO.



Then your bone marrow cannot make enough red blood cells. This causes anemia.

**Shots of EPO 1-3 times each week can get your red blood cells back to normal.**



## Kidney-Brain Connection

If your kidneys fail, you may not be able to learn as well as other people your age because:

1) Toxins (poisonous substances) that are normally filtered out of blood by the kidneys build up in your blood and slow down your brain.

2) Anemia keeps your brain from getting oxygen and also slows it down.

3) High blood pressure may keep your brain from functioning at its best.





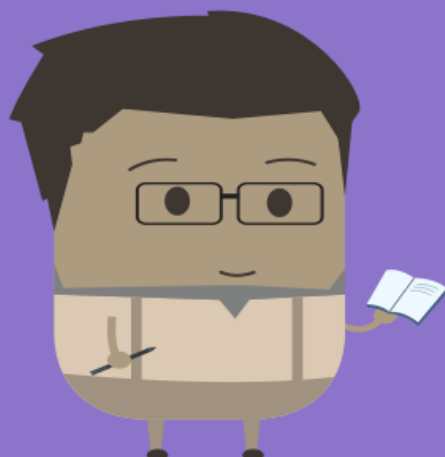
# CKD AND MEDICATION MANAGEMENT

**Week 2**

In this session we will learn about:

What is CKD?

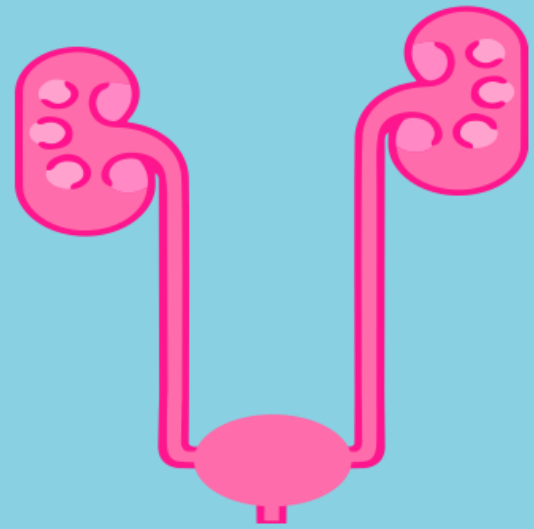
Why is it  
important to  
take  
medications?



# What is Chronic Kidney Disease (CKD)?

Week 2

CKD is a problem with the kidneys that gets worse over time, but it can be managed or slowed down!



## CKD can be “silent”

- This means that you may not feel different.
- By the time you feel sick, your kidneys are very sick.
- Doctors know how sick your kidneys are with blood tests.

What makes CKD happen?

What are the stages of CKD?

How can we fix CKD?

Why did you get CKD?



Let's try and answer some of these questions...Turn the page!

# What makes CKD happen?

Week 2

↪ THERE ARE 2 POSSIBLE ANSWERS

1 You were born with kidney problems

2 Your kidneys became sick when you got older



Either way, doctors know how to help you!

## Why did you get CKD?

It is something that just happens...just like having dark hair or brown eyes



- It is not your fault
- No one is punishing you
- You did not do anything wrong



# Hey Doc! What are some reasons I might get CKD?

Week 2

That's a great question. There are lots of reasons why you may get CKD. The most common causes include:

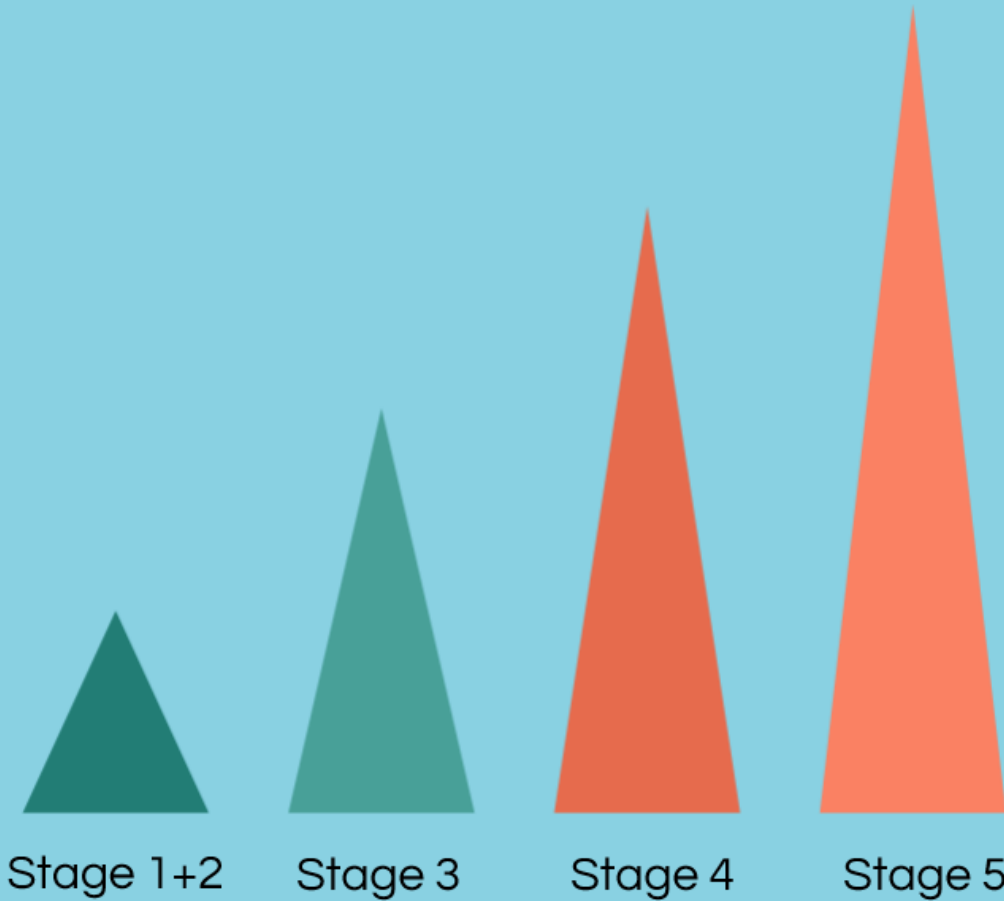
- From diabetes
- High blood pressure
- If you get an infection
- If one of your parents or grandparents had it, you can develop it too.

And many more! If you are not sure why you got your CKD you can ask your doctor.



# What are the stages of CKD?

Week 2



**Stage 1+2** Your kidneys work well

**Stage 3** You need some medicines to help out

**Stage 4** You need more medicines and maybe shots

**Stage 5** Your kidneys need a lot of help

# Stages of CKD

Week 2

## Stage 1+2

- You might not even feel anything different!
- Your doctor will make sure you eat the right things and keep an eye on your blood pressure.
- You may need to take medications.

## Stage 3

- You might feel tired or have trouble sleeping.
- You may have swelling or pain in your lower back where your kidneys are.
- You may need to follow a specific diet and take medications.

## Stage 4

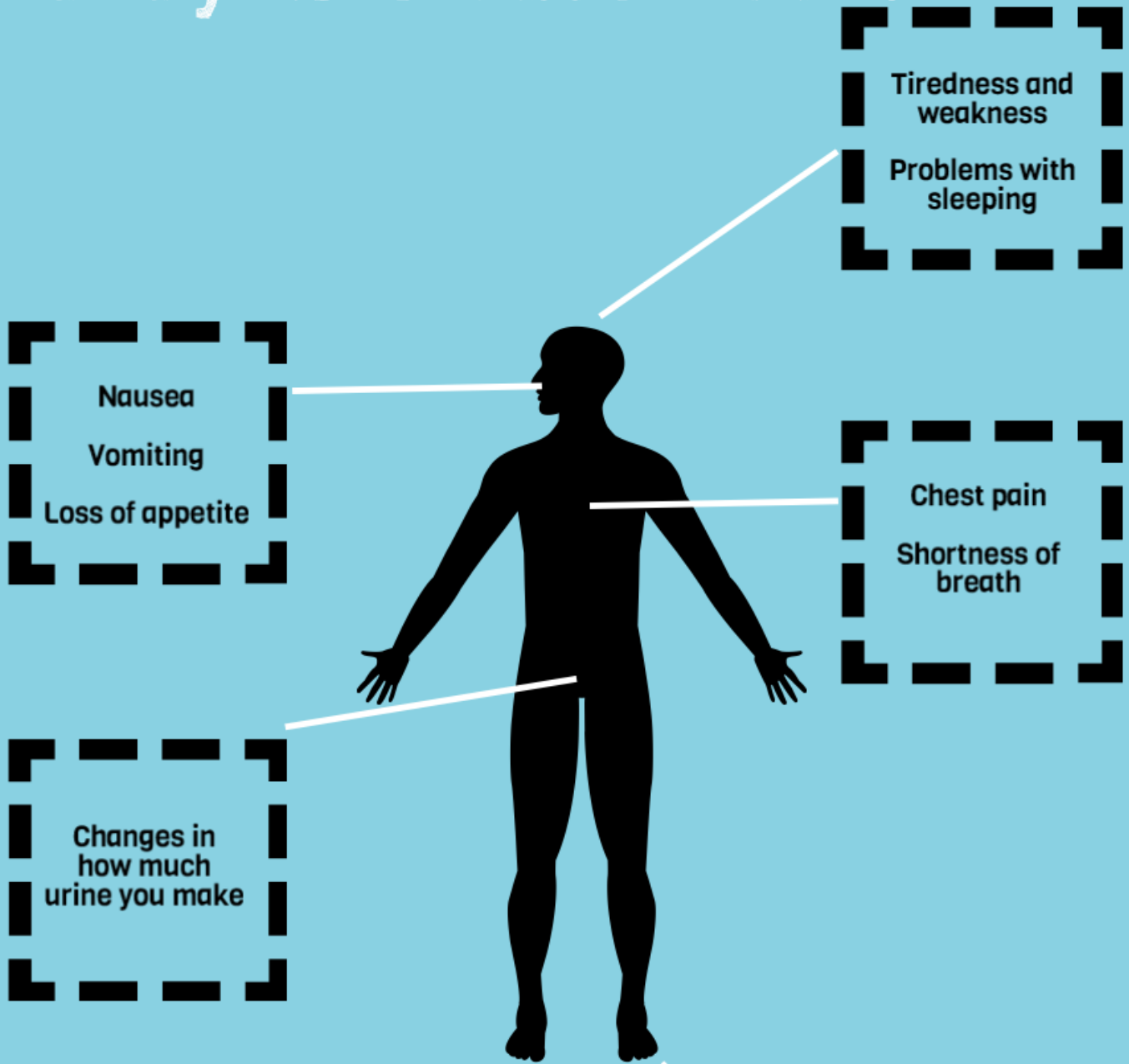
- You might feel the same things from stage 3 (tired, swelling) as well as feeling sick to your stomach (nausea) and vomiting.
- You might have a hard time staying focused on things.
- You may need to follow a special diet and will take medications. -
- You might need many blood tests, and could possibly start DIALYSIS.

## Stage 5

- You might hear this called "End Stage Kidney Disease".
- Your kidneys are very sick.
- You may have the same feelings as stages 3 and 4.
- You may have headaches.
- Your body may make less urine.
- You will need to follow a special diet and take medications.
- You might need many blood tests to see how your kidneys are doing.
- You will probably start dialysis and get put on a waiting list for a kidney TRANSPLANT.



# What are some things I may feel in my body if I have CKD?



**EXPERT BOX!**  
These things you feel are called "SYMPTOMS."  
If you notice a new symptom, tell your doctor as soon as you can!

# How do you treat CKD?

Week 2

Medications to help your blood pressure.

Medications to make your bones stronger.

Medications to help with swelling.

Changing the foods you eat and what you drink.

Medications to help with your energy and weakness.

There are lots of ways I can help treat your CKD!

Having a more healthy and active lifestyle.

Medication shots to increase red blood cells.



# How do the kidneys get extra help in Stage 5 CKD?

Week 2

## Two ways to help the kidneys:

- 1) A Kidney Machine: Called "DIALYSIS"  
- A dialysis machine cleans your blood when your kidneys cannot on their own
- 2) A new kidney: Called a "TRANSPLANT"

### Kinds of Dialysis

#### BLOOD DIALYSIS

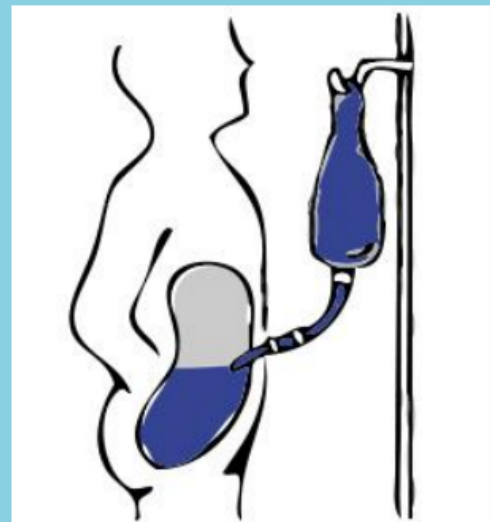
Blood leaves your body, gets cleaned by a machine and returns to you



**EXPERT BOX**  
Doctors call blood dialysis  
"HEMODIALYSIS"

#### BELLY DIALYSIS

Fluid goes in and out of your "belly" to clean your blood



**EXPERT BOX**  
Doctors call belly dialysis  
"PERITONEAL DIALYSIS"



# How do the kidneys get extra help in Stage 5 CKD? (continued)

Week 2

## Kidney Transplant

Q: What is a transplant?

A: A transplant is a new kidney from someone else. Sounds weird, right? But it is OK! Most people with Stage 5 CKD get a transplant.

Kidney transplants are like keys and keyholes. Only a few special keys will turn the keyhole to your front door. Only a special kidney will fit and work in your body.



Q: How can you get a transplant?

A: Everyone has two kidneys, sometimes people can give one of theirs to another person who needs one. You can get a kidney from an ORGAN DONOR.

Q: How long can you keep your kidney transplant?

A: You can keep a kidney transplant for many years (10-12 if you take care of it!)  
It will last longer if you take your medicines!

# How do the kidneys get extra help in Stage 5 CKD? (continued)

Week 2

Q: Can your new kidney stop working?

A: Yes, if you do not follow your doctor's advice.

Q: What is the #1 cause of losing a kidney transplant?

A: NOT TAKING YOUR MEDICINES!

Q: What happens if you lose your transplant?

A: You will need to go back to dialysis.

People who need a transplant may have to wait a long time before they find the right one.

If you have a transplant, it is very important to take care of it! Always take your medicines and follow your doctor's directions!

# Your Medicines

Week 2

ACTIVITY: List your medicines on the left and what they do on the right!!

*Medicine Name*

*What Does it Do?*

-----

-----

-----

-----

-----

-----

-----

-----

-----

-----

-----

-----

List other medicines you take or know about and what they do:

-----

-----

-----

-----

You can find a list of common medicines in the back of this book!

# Taking other Medicines with Kidney Disease

Week 2

Since your kidneys do not filter as well as they used to, you need to be careful about all the medicines you take.



Your doctor prescribes the medication that is best for you. Remember, you can always check with the pharmacist if you have any questions or concerns.



Some medicines can also harm your kidneys. Make sure you ask your doctor which medicines are unsafe!



Your doctor can help you to make sure that you are taking the right medicines and in the right amounts.



## Summary

- CKD is a problem with the kidneys that can get worse and worse.
- There are 5 stages of CKD.
- If you get to stage 5 you will either need a transplant or dialysis.
- Taking your medicines is important to keep you and your transplant healthy!
- You need to talk with your doctors before taking other medicines that are different from the ones they tell you to take.



# Check-In questions:

Week 2

1. What are the names of the two types of dialysis?

- a) kidney dialysis and peritoneal dialysis
- b) blood dialysis (hemodialysis) and belly dialysis (peritoneal dialysis)
- c) blood dialysis and kidney dialysis
- d) phosphorus dialysis and kidney dialysis

2. What is the #1 way to lose your transplant?

- a) Injury
- b) Sickness
- c) Not taking medicines
- d) Not eating the right foods

3. At what stage of CKD would you need a transplant or dialysis?

- a) 2
- b) 3
- c) 4
- d) 5

4. True or False: You need to talk with your doctors before taking other medicines that are different from the ones they tell you take.

- a) True
- b) False

5. True or False: If you get a transplant then the new kidney will work for the rest of your life.

- a) True
- b) False

# MAKING HEALTHY CHOICES



In this session, we will talk about how eating right and making healthy choices can help you manage your kidney disease.

# What Should You Be Doing to Stay Healthy?



When you have CKD, some foods can be bad for you. Eating the right way is important to keep you healthy.

You can ask your doctor or nurse if what you are eating is good or bad for you.

You can also learn to read nutrition labels on food to help you make healthy choices.



# Food and CKD

Week 3

Some foods may be better for your kidneys than others.

Try to eat homemade meals to have more control over what you eat.

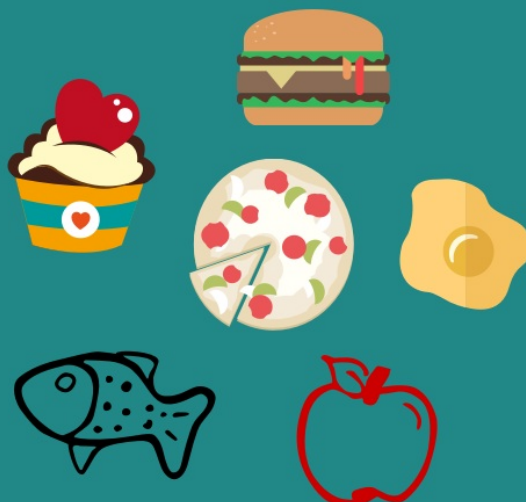
DID YOU KNOW

Most of the salt people eat comes from prepared foods, not from the salt shaker.

Activity: Sort the foods by what you should eat more or less of

More

Less



# Making Healthy Choices

Week 3

## Eat the right amount and the right types of protein.

Why? To help protect your kidneys.

Animal proteins create more acid than plant proteins.  
Too much acid can harm your kidneys.

Activity: Circle the animal proteins & underline the plant proteins

Grains   Beans   Dairy   Nuts  
Fish   Eggs   Chicken

Answer: Dairy, eggs, chicken, and fish are animal proteins. Beans, nuts, and grains are plant proteins.

## Choose foods that are good for your heart

Why? To protect your heart, blood vessels, and kidneys



### Heart Healthy Foods:

Lean meat  
Chicken without skin  
Fish  
Beans  
Vegetables  
Fruit  
Low fat milk, yogurt, and cheese

You need to monitor your sodium in any CKD stage. Potassium and phosphorus levels should be more closely monitored in stages 4 and 5. Your nutrition plan will be special to you, so ask your doctor what it should be.

Important minerals to monitor with CKD:

Sodium  
Potassium  
Phosphorus

# Monitoring Sodium

Week 3

## Choose and prepare foods with less SODIUM.

Why? To help keep your blood pressure at a healthy level.

Fresh food has less salt than packaged food!

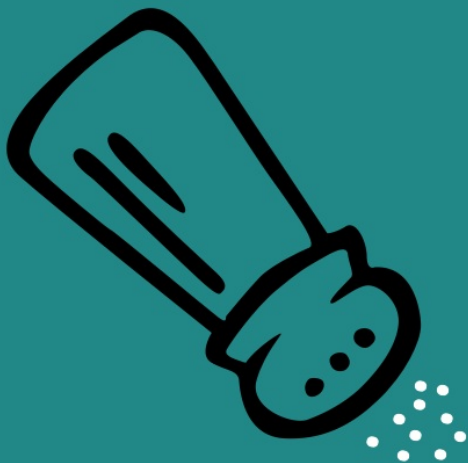
sodium = salt



## Look for Food Labels that Say:

Reduced sodium  
Light in sodium  
No salt added  
Lightly salted

Sodium free  
Low sodium  
Unsalted



Aim for less than  
1,500 milligrams of  
sodium each day.



# Monitoring Phosphorus

Week 3

## Choose foods with less phosphorus

Why? To help protect your bones and blood vessels.

eat more of these

eat less of these



Foods with Less Phosphorus



- Fresh fruits & vegetables
- Breads, pasta, rice
- Rice milk (not enriched)
- Corn and rice cereals



Foods with More Phosphorus



- Meat, poultry, fish
- Bran cereals and oatmeal
- Dairy foods
- Beans, lentils, nuts



# Monitoring Potassium

Week 3



## Choose foods with the right amount of potassium

Why? To help your body work correctly. When you have too much or too little potassium, things can go wrong!

Most people with CKD are supposed to eat less potassium. Need some ideas of what to eat more or less of?

Start here...

### Foods with More Potassium

- Oranges, bananas
- Potatoes, tomatoes
- Brown and wild rice
- Bran cereals
- Dairy foods
- Whole wheat bread and pasta
- Beans and nuts

### Foods with Less Potassium

- Apples, peaches
- Carrots, green beans
- White bread and pasta
- White rice
- Rice milk (not enriched)
- Cooked rice and wheat cereals, grits

# Choosing Drinks

Week 3

Drink water  
instead of soda  
or juice!

You can sometimes  
have lemon or lime  
soda, homemade iced  
tea, and lemonade if  
you do not want water.  
If you are limiting  
potassium, apple,  
grape, or cranberry  
juice can be good  
options.

Drink less dark  
soda, fruit punch,  
and bottled iced  
tea. If you're  
limiting  
potassium, try to  
avoid orange juice



# Tips to Eat Smart: Review & Activity

Week 3

If you have CKD it is important to:



- Know **WHAT** food you can eat
- Know **WHY** you have to avoid certain food
- **AVOID** eating packaged or pre-made food, try to eat fresh food!



Think you got it?

Name 3 of your favorite foods that you should eat more of:

---

Why are these good choices?

---

---



# Food Labels: The Basics



What can you learn from a **FOOD LABEL?**

- How much of the package is one serving size.
- What ingredients are in the food.
- What nutrients are in the food.
- How much of each nutrient there is.

The **SERVING SIZE** tells you how much you should eat at a time

One serving has 660 milligrams of sodium

| <b>Nutrition Facts</b>  |                              |                |              |
|---|------------------------------|----------------|--------------|
| Serving Size 1 cup (228g)   |                              |                |              |
| Servings per Container 2  |                              |                |              |
| Amount Per Serving  |                              |                |              |
| <b>Calories</b> 280   | <b>Calories from Fat</b> 120 |                |              |
| % Daily Value*  |                              |                |              |
| <b>Total Fat</b> 13g  |                              |                | 20%          |
| Saturated Fat 5g  |                              |                | 25%          |
| Trans Fat 2g  |                              |                |              |
| <b>Cholesterol</b> 2mg  |                              |                | 10%          |
| <b>Sodium</b> 660mg   |                              |                | 28%          |
| <b>Total Carbohydrate</b> 31g   |                              |                | 10%          |
| Dietary Fiber 3g  |                              |                | 0%           |
| Sugars 5g   |                              |                |              |
| <b>Protein</b> 5g   |                              |                |              |
| Vitamin A 4%  | •                            | Vitamin C 2%   |              |
| Calcium 15%   | •                            | Iron 4%        |              |
| <small>*Percent Daily Values are based on a 2,000-calorie diet. Your daily values may be higher or lower depending on your calorie needs.</small> |                              |                |              |
|   | <b>Calories:</b>             | <b>2,000</b>   | <b>2,500</b> |
| Total Fat   | Less than                    | 65g            | 80g          |
| Sat Fat   | Less than                    | 20g            | 25g          |
| Cholesterol   | Less than                    | 300mg          | 300mg        |
| Sodium  | Less than                    | 2,400mg        | 2,400mg      |
| Total Carbohydrate  |                              | 300g           | 375g         |
| Fiber   |                              | 25g            | 30g          |
| <b>Calories per gram:</b>   |                              |                |              |
| Fat 9   | •                            | Carbohydrate 4 | • Protein 4  |

This package has 2 servings

This package has 28% of the Daily Value of sodium in one serving. You should try and eat foods with less than 20% of your daily value

Remember, in general people with CKD should try to have less than 1500 mg of sodium a day.



# Tips for Reading Food Labels

1. Check the label for sodium.
2. Check the ingredient list for phosphorus and potassium.
3. Look for claims on the label like "low SATURATED FAT" or "sodium free."



If you know how to read a food label you will know which foods are better for you.



Sometimes even if a food looks healthy, it might not be!

# Checking Ingredients

Week 3

You can normally find a list of ingredients at the bottom of the food label.

Some foods may be better or worse for you.

Reading the ingredient list can help you decide whether you should eat the food or try something different.

## What to Look for on the Ingredient List

Phosphorous or words with PHOS.  
A lot of packaged foods have phosphorus. When the ingredient list has PHOS on the label you should choose a different food.

Examples: PHOSphoric acid, calcium PHOSphate.

Potassium can be hidden in some places like canned soups or tomato products. Depending on what your doctor has told you, limit foods with potassium.


# Healthy Living

Week 3



## Exercise!

The more active you are, the healthier your kidneys and heart will be!

A yellow sticky note with a pencil tip pointing to it from the top left. The note has a dark grey ribbon at the top.

Write down some activities that you like to do to stay fit

---

Protect your kidneys! Do not take risks!



Do NOT drink alcohol or use illegal drugs.

Alcohol or illegal drugs can hurt you and your kidneys!

# Making Healthy Choices

Week 3



## Do NOT Smoke!

Smoking can hurt you and your kidneys, even if you are doing everything else perfectly!





# SUMMARY

Week 3

What you eat and drink affects how healthy you stay with CKD.

There are 5 main steps to help you eat right as you manage your CKD:

- 1) Eat the right amount and right types of protein.
- 2) Choose foods that are good for your heart.
- 3) Choose foods with less sodium.
- 4) Choose foods with less phosphorus.
- 5) Choose foods that have the right amount of potassium.



Pay attention to what you are drinking (choose water over soda and juice).

You can also stay healthy by exercising, not smoking, and not drinking or using illegal drugs.

# Check-In Questions

Week 3

1) Which of the following ingredients should you pay attention to when reading food labels if you have CKD?

- a) sodium
- b) protein
- c) phosphorus
- d) potassium
- e) all of the above

2) Which of the following has animal-protein in it?

- a) chicken
- b) fish
- c) eggs
- d) all of the above

3) Which of the following is a food that is healthy for your heart?

- a) vegetables
- b) potato chips
- c) ice cream
- d) rotisserie chicken

4) True or False: You should make food with less salt and sodium.

- a) True
- b) False

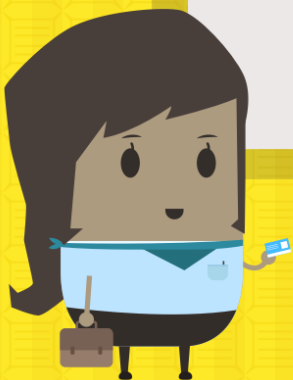
5) Which of the following is a good tip to keep a healthy lifestyle?

- a) exercise
- b) do not smoke
- c) do not drink alcohol or consume illegal drugs
- d) all of the above

# INTRODUCTION TO SELF-MANAGEMENT

**week 4**

In this session we will talk about what self-management is and why it is important. We will start to learn some things that you can do to care for you Kidneys.





**BRAINSTORMING!**

List three things that you do now or will need to do to manage your condition. Don't know? Ask your doctor, nurse, or parent!

1.

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2.

---

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3.

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# What is Self-Management?

As you get older, you need to learn about how to manage your disease on your own! You will need to do many different things, like:

- Getting medication refills
- Always taking your medicines (on your own!)
- Setting up doctor appointments
- Asking questions about your condition

All of these things, and more, make up something called self-management.

## **SELF-MANAGEMENT:**

what a person with a chronic disease does to control his/her illness and stay healthy.



In this section we will talk more about self-management skills, and why it is important for you to have them!



# Reading a Prescription Label

Week 4

We know that PRESCRIPTION (medicine) labels can be confusing, but they have a lot of important information that you should always read! Let's break it down together to see how easy it can be!

Pharmacy name and address: Main Street Pharmacy, 1200 Main Street North, Minneapolis, MN

Pharmacy phone number: (612) 555-1234

Prescribing Doctor: Dr. R. Wilson

Rx No: 300443

Date of prescription: 01/04/2005

Your name: JOHN JOHNSON

Medication name: Zocor Tabs Mfg Merck

Instructions on how to take your medicine: Dose: TAKE ONE TABLET BY MOUTH, DAILY.

Number of pills: Qty: 30

Number of refills left: REFILLS: 3

Date of last refill: BEFORE 12/08/05

Here are some tips for refilling your prescriptions:

- Refill your prescription either by phone or online 2 weeks before you run out
- Read the label to see how many refills you have left before you need to ask your doctor for a new prescription
- Ask about getting 90-day refills to make it easier to always have your medication
- Ask your parent about how your medicines are refilled



With new technology sometimes you do not have to call the pharmacy anymore to get your prescriptions refilled! You can order them online or through the mail.



For example, at UNC you can send a message through MyChart to fill your prescriptions!

# ACTIVITY TIME!

Week 4

Now it's time to test your knowledge! Below is an example of a prescription drug label. Using the numbers on the prescription below, where would you find the following?

If you were trying to tell your doctor the name of your medication where would you look? \_\_\_\_\_

If you ran out of your medication, where would you look to see if you can get more? \_\_\_\_\_

Where would you look to see how often you should take your medicine? \_\_\_\_\_

Where would you look to see when this medication expires (goes bad)? \_\_\_\_\_

The image shows a prescription drug label for Amoxicillin 500mg capsules. The label is white with black and blue text. It includes the pharmacy name 'Local Pharmacy' with an address and phone number, the doctor's name 'DR C. JONES', the patient's name 'JANE SMITH' with address, and the medication name 'AMOXICILLIN 500MG CAPSULES'. It also contains dosage instructions, a quantity field, a refills field, and an expiration date. A barcode is on the right side. Ten numbered callouts (1-10) point to specific parts of the label: 1 points to the quantity field, 2 to the medication name, 3 to the dosage instructions, 4 to the patient name, 5 to the pharmacy name, 6 to the pharmacy address, 7 to the doctor's name, 8 to the phone number, 9 to the expiration date, and 10 to the refills field.

6 7 8 9

5

4

3

2

1

10

**Local Pharmacy**  
123 MAIN STREET  
ANYTOWN, USA 11111 (800) 555-5555

DR C. JONES

NO 0060023-08291 DATE 06/23/09

JANE SMITH  
456 MAIN STREET ANYTOWN, US 11111

TAKE ONE CAPSULE BY MOUTH THREE  
TIMES DAILY FOR 10 DAYS UNTIL ALL TAKEN

AMOXICILLIN 500MG CAPSULES

QTY MRG  
NO REFILLS - DR. AUTHORIZATION REQUIRED

USE BEFORE 06/23/12  
SLF/SLF



# APPOINTMENTS

Appointments are a time for your doctor to check on your health. They are also a chance for you to ask questions about your care. It is very important for you to always go to your appointments. If you cannot make it, be sure to cancel on time, and always call ahead to reschedule!

It's always good to have questions to ask your doctor- take this space to write down questions for your next appointment!



**#1**

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**#2**

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**#3**

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Always set up your next appointment before you leave the doctor's office!



# Communicating with Your Doctor

Week 4

## Contacting your doctor with questions

You do not have to wait until your appointment to ask your doctor a question. You can e-mail or call them, and they will be happy to help you!

Get their e-mail or phone number to contact them if you have questions about your medications, diet, symptoms, etc. Fill out information on your doctor(s) below!

Contact Information for your doctor(s)

Name:  
E-mail:  
Phone #:

Name:  
E-mail:  
Phone #:

Name:  
E-mail:  
Phone #:



# Calling your Doctor

## Calling your doctor sounds easy, right?

Calling your doctor's office is easy, but sometimes you may not get your doctor right away. Below are some tips for when you call your doctor.

Make sure you know the name of your doctor! If you call the main hospital number you will need to tell them this.

If you get put on hold BE PATIENT! Your doctor will get to you as soon as they can.

**IF YOU HAVE AN  
EMERGENCY HANG UP  
AND CALL 911!**



Have your questions ready on a piece of paper. Write down the answers your doctor gives you.

# ASKING QUESTIONS

Week 4

You may have only just found out about your condition, or maybe you have had it your whole life! Either way, you will probably have questions about your health sometimes. This section is about questions for your doctor about symptoms, medications, and tests or treatments!

## Questions for your Doctor

You are probably used to answering your doctor's questions, not asking your own. But you have the right to ask questions, too! In fact, you should be able to ask questions about anything you like: it's your body.

Why can't I eat foods that have Phosphorus? What IS phosphorus?




On the next pages we will give examples of questions you can ask your doctor to help you talk about normal things that might be worrying you. It will be helpful to write some down for your next appointment!





Put a  next to questions that you want to ask your doctor!

## Questions About Communicating with your Doctor



Will the information I tell you be kept between us?

If I need to, can I see you without my parents knowing about the visit?

Is it OK for me to see you without my parents in the room?

---

## Questions About an Illness or Symptom

- What is wrong with me?
  - Can you draw me a picture or show me what's wrong?
  - What causes this type of problem?
  - Is this serious?
  - Will there be any long-term effects of this problem?
  - Can I give this illness to someone else, and if so, how and for how long?
  - Are there any activities or foods I should avoid until I'm better?
  - When can I return to school or work?
  - How can I prevent this from happening again?
-



## Questions About Medications

- What does this medicine do?
- What will happen if I don't take it?
- Should I stop the medicine if I feel back to normal?
- What are the side effects?
- How long should I take it?
- What if I accidentally miss a dose?
- If I do not notice any improvement, how long should I wait before calling you?



## Questions About Tests and Treatments

- Why is this test needed?
- How soon must I get the test?
- What will happen if I don't get the test?
- Are there any risks involved?
- Will it hurt? If so, is there anything we can do to lessen the pain?
- Can you perform the test or treatment in your office, or will I need to go to a lab or other facility?
- Are there any side effects?
- How should I prepare for the test or treatment?
- What side effects or changes should I report to you?



Did you think of any other questions you want to ask? Write them down here!

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# SUMMARY

Week 4

The more questions you ask, the more you will discover about your body. When you know what is going on with your body, you can take better control of your own health — today and in the future.

1. Self-management is learning to manage your disease as you get older so that your parents do not have to help you.
2. You will need to learn about your medicines, like which ones you take, why, when, and how you take them.
3. You will need to learn to make your own doctor appointments and refill your medications.
4. Asking questions to your doctor is important to help you keep up with your disease. You can ask questions related to:

- ★ Communication with your doctor
- ★ Your illness or symptoms
- ★ Medications
- ★ Tests and treatments
- ★ Anything else you can think of or have questions about!

# CHECK-IN QUESTIONS

1. How far in advance should you refill your prescription?
  - a. 1 day
  - b. 5 days
  - c. 2 weeks
  - d. 1 month
2. Which of the following is important to know about your medications?
  - a. When you take them
  - b. How you take them
  - c. Why you take them
  - d. All of the above
3. Which of the following would be a good question to ask your doctor about your condition or symptoms?
  - a. How can I prevent this from happening again?
  - b. Will there be any long-term effects of this problem?
  - c. Is this serious?
  - d. All of the above
4. True or false: Asking lots of questions to your doctor can help you learn more about your health condition.
  - a. True
  - b. False
5. True or false: You have to wait until your doctor's appointment to ask your doctor questions.
  - a. True
  - b. False



# BECOMING INDEPENDENT

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**Week 5**



**In this session, we will learn how to prepare for changes that may happen as you get older. We will also teach you things you will need to do to become more independent.**



# Taking Your Medications

Taking medications is a big part of staying in control of your chronic condition.

You might have a lot of medicines that you have to take everyday, and it might seem scary or overwhelming.

In this section, we will talk about why taking medications is so important. We will also talk about things that might make it easier to remember to take your medicines.

Why do people not take their medicines? They:

- Forget
- Do not understand their medical condition
- Believe that nothing bad will happen
- Want to be like everyone else
- Do not feel sick anymore
- Do not like how medicines make them look or feel
- Do not see any problems if they miss their medicines
- Do not think that the doctors or nurses can tell when they are not taking medications



What are some reasons why you do not take your medicines?

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It is always important to take your medications - even if you might not like it.

Doctors can tell if you take your medications or not by testing your blood.

If you have discomfort after taking your medications, let your doctor know!

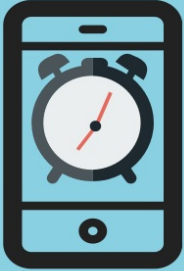
If you have a hard time remembering to take your medicines, we will also talk about some ways to help on the next page.

# Strategies for Remembering to Take Your Medications

- Use a PILLBOX



- Set an alarm on your phone



- Pick something you do everyday, and take medicines at the same time, like:



Getting dressed

Eating your breakfast



Brushing your teeth

List 3 strategies that you will use to help you remember to take your medications. Be creative! You can use more than the ones listed above.

1) \_\_\_\_\_  
2) \_\_\_\_\_  
3) \_\_\_\_\_

# Finding a New Doctor



If you found out about your condition as a child, you were most likely treated by a PEDIATRIC NEPHROLOGIST (a doctor who treats kids with kidney problems). As an adult, you will need to be treated by an ADULT NEPHROLOGIST.

You probably have known your doctor for a long time, and it might be scary to you to see a new one. Don't forget that any doctor you see will care about you - it's their job to keep you healthy!

## Expert Box! (for people 16 or older)

### Steps to Finding a Doctor who Treats Adults

1. Ask the doctor you see now for a "referral."  
- A referral is when your current doctor recommends you to a new one.
2. Explore your options and meet with your new doctor.
3. If you like the new doctor, tell your current doctor that you would like to switch.
4. Ask your current doctor to send your medical records to your new doctor.  
- In order to get your records sent to a new doctor, you have to sign a CONSENT FORM. Just ask the office staff in the clinic to help you!





# Making Appointments

The first thing you have to do before seeing any doctor is make an appointment. Have you ever made a doctor's appointment by yourself? Let's try it!



If your parents usually make your appointments, be sure to check with them to make sure it's okay to call your doctor.

1. Make sure to call during office hours! Usually, this will be between 8am-5pm.
2. When someone answers, tell them you would like to schedule an appointment with Dr. [your doctor's name].
3. They may tell you when your doctor has time to see you or ask you when you are able to come in. Choose an appointment time that works for you.
4. They will ask you the specific reason why you want to see your doctor. Let them know if there is something you will want to talk to your doctor about - like a new symptom or a problem with a medication!
5. Write down the date and time you have set up to see your doctor. Don't forget it! Usually someone will call to remind you about an upcoming appointment.

That's it! You've just scheduled your own doctor appointment. Now, write down the phone numbers of the doctor's offices that you will call to make appointments.

OFFICE/CLINIC NAME

PHONE NUMBER

Nephrology Clinic/ACC

984-974-5706

# HEALTH INSURANCE

When people are sick they may need to go see a doctor or even go to the hospital. A lot of times they will have tests done and then take medications to get better. All of these things cost MONEY, and usually a lot of money.



You can think of health insurance as money to help pay for when people get sick. Health insurance helps pay for hospital bills, visits to the doctor, tests, medications, and many other things you need to stay healthy.

## DO YOU KNOW?

If you are on dialysis or have a transplant, you automatically get Medicare (a type of health insurance) to help pay for it!

Go to  
[www.medicare.gov](http://www.medicare.gov) to  
learn more!





When you have a chronic condition like CKD, it is very important to have health insurance because you might need to go to the doctor or take medications more often than other people. Without health insurance to help pay for these things, it would be very expensive!



## Public Insurance vs. Private Insurance

There are two types of insurance: public and private. Check out some of the differences between them!

### Public

- Paid for by the government
- People with low income may qualify for public insurance
- Examples: Medicaid, Medicare

### Private

- Paid for by you or your parents' EMPLOYER
- It can also be paid for on your own, or "out-of-pocket"
- Examples: Blue Cross Blue Shield, Cigna, United Health

## Expert Box!

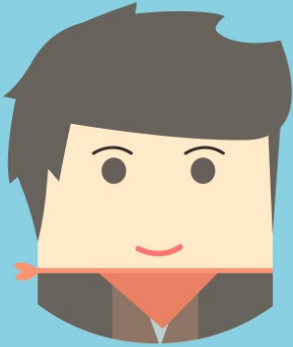
Depending on what kind of health insurance you have, you might need to reapply as early as age 18!

You can visit <http://www.healthcare.gov> to find information on comparing health insurance plans, or call (800) 318-2596 to speak with someone about your options. Try contacting an insurance company with your parents' help, so you can practice for when you will need to do it as an adult!



# ACTIVITY TIME!

Week 5



What do I know about my health insurance?

List answers to the questions below. If you do not know the answer then you can ask your parent!

1) What is health insurance and why is it important to have?

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2) Who is your current health insurance provider?

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3) At what age will my health insurance coverage end?

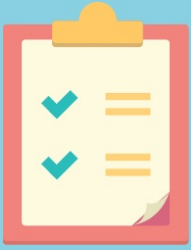
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4) How can I get health insurance for myself when I am an adult?

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# Summary



- 1.** It is important to ask your doctor for a referral when you need to find a new doctor.
- 2.** There are many reasons why people do not take their medicines...but your doctor can tell if you do not!
- 3.** Use strategies to help you remember to take your medicines.
- 4.** Health insurance helps cover your medical expenses.
- 5.** There is private and public health insurance.

# Check-In Questions

---

Week 5

1. What type of insurance do you get if you receive a kidney transplant or are on dialysis?
  - a. Medicaid
  - b. Medicare
  - c. Private
  - d. None
  
2. Which of the following are strategies to help you remember to take your medicines?
  - a. Put them in a pill box
  - b. Set an alarm on your phone
  - c. Take them at the same time that you do something else every day
  - d. All of the above
  
3. Why is health insurance important to have?
  - a. It allows you to go to the doctor
  - b. It allows you to go to the emergency department
  - c. It is not important for everyone to have
  - d. It helps cover your medical expenses
  
4. True or false: your doctors and nurses can tell when you do not take your medicines.
  - a. True
  - b. False
  
5. Which is the best way to find a new doctor?
  - a. Ask a friend
  - b. Ask your current doctor or nurse for a referral
  - c. Search the internet
  - d. I don't need to find a doctor when I'm an adult

# REVIEW AND SELF-ADVOCACY

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**week 6**



In this session we will go over everything you have learned the past few weeks and teach you skills to help you advocate for yourself!



# THE FINAL session

Congratulations, you have made it to the last week of the self-management workbook!

We have learned a lot! Hopefully you know more about your health condition and how to take care of yourself.

In this last session, we will review information from the last 5 weeks. Then we will talk about how you can advocate for yourself in the health care system.

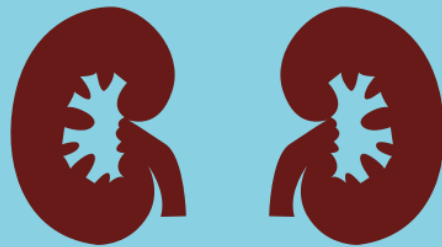
Finally, we will give you some awesome resources to learn more about CKD and ways to connect with other teens like you!



# Week 1 Review

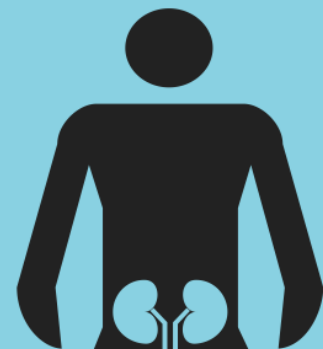
Week 6

## Introduction to the Kidneys



Your kidneys do a lot of things for you! For example, your kidneys:

- Help control Vitamin D for strong bones
- Instruct your body to make red blood cells in your blood
- Dispose of drugs
- Balance acid and fluid
- Eliminate waste
- Send out hormones to control blood pressure



Drugs, Acid,  
Fluid, Waste

# Week 2 Review

Week 6

## Chronic Kidney Disease (CKD) and Medication Management

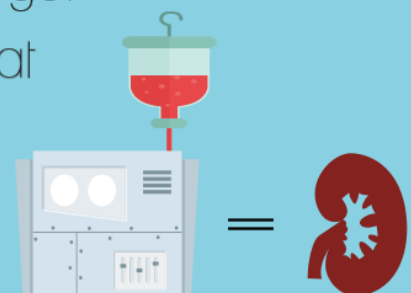
- ★ CKD is a problem with the kidneys that can get worse if it is not treated, but it can be controlled!
- ★ When you have CKD, you may not feel different. It can be "silent."
- ★ CKD has 5 stages. If you get to stage 5 your kidneys will need extra help to work well (like dialysis or transplant).



- ★ There are two ways to help the kidneys:

1. Dialysis: a kidney machine that cleans your blood

2. Transplant: a new kidney



- ★ Taking medicines is a very important part of caring for yourself with CKD!





# Week 3 Review

## Making Healthy Choices


Week 6




Eating right is also necessary to keep you healthy with CKD!

- It is important to know what foods to have more or less of.

### 6 Tips for Eating Right with CKD

1. Eat the right amount and the right types of protein. 

2. Choose foods that are healthy for your heart. 

3. Choose and prepare foods with less salt and sodium. 

4. Choose foods with less phosphorus, for example, lightly salted popcorn instead of peanuts. 

5. Choose foods with the right amount of potassium. 

6. Choose water over soda or juice! 



Reading food labels is very important so you know which foods are better for you!

# Week 4 Review

Week 6



## Introduction to Self-Management

As you get older, you will need to learn how to manage your disease without the help of your parents (this is called self-management.)

Things you need to know or do as you get older:

★ Know all of your medications!



- What they are.
- How and when you take them.
- What they do.

★ Refill your prescriptions and schedule your own doctor appointments.



★ Ask your doctor questions when you are confused or do not know something. This makes you knowledgeable about your disease.



Knowledge is powerful!



# Week 5 Review

Week 6

## Becoming Independent



- ★ Health insurance helps cover your medical expenses. If you have CKD, health insurance is very important because you might need to take a lot of medicines and go to the doctor's office a lot.

- ★ There are two types of health insurance:

1. Public health insurance
2. Private health insurance



- ★ When you get older, you will need to find an adult doctor. To do this, you can ask your doctor for a referral.

Ask me for a referral!





Week 5 Review Continued...

# Taking Your Medicines

★ A lot of people do not take their medicines because they:

- Forget
- Do not think anything bad can happen
- Do not think doctors and nurses can tell when they are not taking medications

★ Doctors and nurses can tell if you do not take your medications, so it is important that you take them to stay healthy!



★ Strategies to help you remember to take your medicines include:

- Putting them in a pill box
- Setting an alarm on your phone or computer
- Taking them at the same time you do something every day, like getting dressed or brushing your teeth



# Self-Advocacy

Week 6



**As an adult, you need to be an advocate for yourself.**

## What is Self-Advocacy?

SELF-ADVOCACY is many things, including:

- **Learning how to speak up for yourself**
- **Making decisions about your own life**
- **Knowing what interests you**
- **Finding out who will support you in your journey**
- **Knowing your rights and responsibilities**
- **Problem solving**
- **Listening and being knowledgeable**
- **Reaching out to others for help and friendship**
- **Learning about SELF-DETERMINATION**

What is one thing that you will start doing to advocate for yourself and your health?

I will...

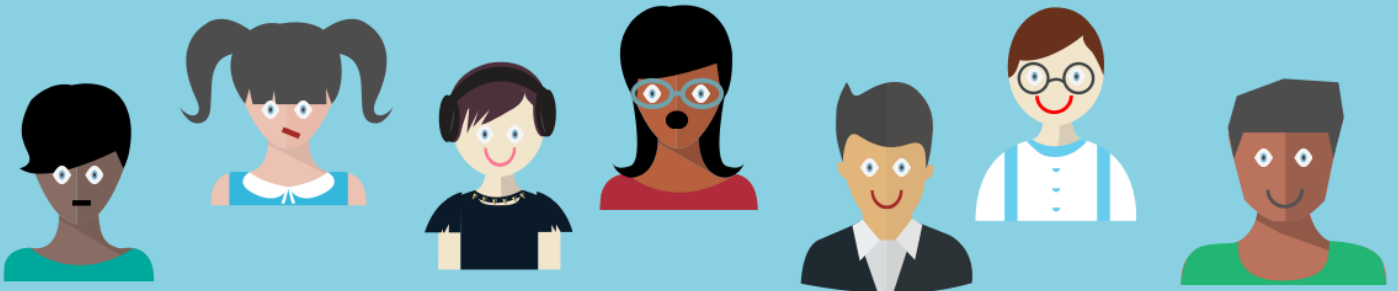
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# Why do I need to advocate for myself?



Everyone is different, and nobody knows you better than yourself!



Even though your parents may have helped you a lot with living with CKD, you are getting older and probably have your own questions.

- It is important to know yourself and know what questions to ask your doctor.
- This way you can plan together for your health.









Week 6

# Learn About the Healthcare System



- Start asking questions at your doctor's appointments! Write them down before going to your appointment.
- Learn how to make your own doctor's appointments.
- Understand the process of transitioning to adult healthcare (we learned about this in the last session!)
- Understand and learn about how your health insurance works!



Knowing the healthcare system will make it easier for you to be an advocate for yourself!





# Be More Independent!

Try and start seeing your doctor on your own for some of your appointments or let your parents attend part of the appointment.

If your parent wants to stay in your appointment, then make sure YOU do the talking.

Make sure that YOU are the one having the conversation with your doctor and not your parent.

It might be easier to do this if you think of questions ahead of time

You can use this space to write down any questions you think of before your next doctors visit.

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\_\_\_\_\_

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\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



# Speaking Up For Yourself Can Be Scary

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- Advocating for yourself can be a scary thing to do! Especially when your parents have taken care of you your whole life.



- Remember that sometimes the hardest things in life can be the most rewarding.



- If you speak up for yourself you will start to feel more comfortable with your doctor and with your disease overall.







# Connecting with Other People with CKD

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## Starbright World:

- The first-ever online social network for teens with chronic and life-threatening medical conditions, and their siblings. Members are able to connect globally with others experiencing similar medical journeys.  
<https://www.starbrightworld.org/>



## Victory Junction

- A camp in North Carolina for kids with chronic illnesses! This is a great place to meet other teens with CKD!  
<http://www.victoryjunction.org/>

## Ben's Friends



- Another online network to connect with teens with kidney disease! They have online chat rooms and Facebook pages. Check out <http://www.bensfriends.org/>



## Renal Support Network



- A place to get information about CKD and connect with others with kidney disease. Check out <http://www.rsnhope.org/about-rsn/>



# Summary

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You have learned a lot over the past 6 weeks!  
Congratulations on completing this program!

Take all of these skills and put them to use in your everyday life and when you go to your doctors' appointments.

If you still have questions about anything you learned, you can ask your doctor or nurse.

Use your strengths and advocate for yourself! You will do great things!



# Check-In Questions

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- 1) What is self-advocacy?
  - a) Learning to read the time
  - b) Learning to speak up for yourself
  - c) Telling your friends not to drink alcohol
  - d) Being independent and not having to go to your doctor's appointments
  
- 2) True or False: Learning about the healthcare system will help you be a better self-advocate.
  - a) True
  - b) False
  
- 3) True or False: You should rely on your parents for the rest of your life to take care of your health condition.
  - a) True
  - b) False
  
- 4) Which of the following websites is somewhere that you can talk to others with CKD?
  - a) Starbright World
  - b) Ben's Friends
  - c) Renal Support Network
  - d) All of the above





# Certificate of Completion

Congratulations!

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Your name here

You have completed the Chronic Kidney Disease  
Information Packet!

Remember that there are a lot of things that you can do to manage and understand your CKD. The more you know about CKD, the more able you will be to take care of yourself as you get older!

If you forget some of the things that you learned, you can always look back at this booklet. If you have other questions, you can talk to your doctor or parents, and there are some great online resources that you can use as well.



# RESOURCES

Want to learn more about CKD?  
Here are some other resources  
that you can use!

## About CKD

<https://www.kidney.org/kidneydisease/aboutckd>

## Advocating for Yourself

<http://www.unckidneycenter.org/BeYourOwnHealthCareAdvocate.pdf>

## Coping Effectively: A Guide for Patients and Their Families

[https://www.kidney.org/sites/default/files/11-10-0503\\_coping.pdf](https://www.kidney.org/sites/default/files/11-10-0503_coping.pdf)

## KidsHealth

<http://kidshealth.org/>

## National Kidney Disease Education Program (NKDEP)

<http://nkdep.nih.gov/index.shtml>

## Overview of Kidney Disease in Children

<http://kidney.niddk.nih.gov/kudiseases/pubs/childkidneydiseases/overview/>

A comprehensive overview of CKD.

## Stages of CKD

<http://www.davita.com/kidney-disease/overview/stages-of-kidney-disease>

## Victory Junction

<http://www.victoryjunction.org/index.php>

Victory Junction offers camps in North Carolina for children with serious illnesses, including kidney disease.

## Video About the Kidneys

[https://www.youtube.com/watch?v=3qOV\\_03Nhyc](https://www.youtube.com/watch?v=3qOV_03Nhyc)

A 2-minute long video about the kidneys and kidney disease.

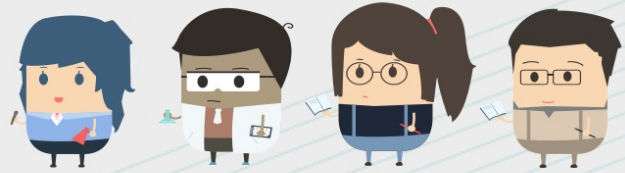
# Medicines to Treat Kidney Disease

Below is a list of some of the medicines your doctor may ask you to take for your CKD. Use this as a guide if you have questions about the medicines your doctor has told you to take!

| Drug                | also known as ...         | Primary purpose  | Secondary purpose                                      |
|---------------------|---------------------------|--|--|
| Amlodipine          | Norvasc                   | Control blood pressure   |  |
| Atenolol            |                           | Control blood pressure   |  |
| Cellcept            | Mycophenolate             | Prevent rejection  |  |
| Cyclosporlin        | Gengraf/neoral/sandimmune | Prevent rejection  | Help kidneys function                                  |
| Enalapril           | Vasotec                   | Control blood pressure   | Decrease protein in urine/protect kidney from scarring |
| Ferrous Sulfate     |                           | Iron replacement that helps your body make more red blood cells      |  |
| Hydrochlorothiazide | Hydrodiuril               | Control blood pressure   |  |
| Imuran              | Azathioprine              | Prevent rejection  |  |
| Lasix               | Furosemide                | Control blood pressure   | Treat fluid build-up/reduce swelling                   |
| Lisinopril          |                           | Control blood pressure   | Decrease protein in urine/protect kidney from scarring |
| Pepcid              | Famotidine                | Decrease amount of acid made in the stomach                          | Treat ulcers and GERD                                  |
| Plaquenil           | Hydroxychloroquine        | Reduce skin problems in lupus and prevent swelling                   |  |
| Prednisone          |                           | Prevent rejection  |  |
| Prograf             | Tacrolimus                | Prevent rejection  |  |
| Renagel             | Sevelamer                 | Prevent the body from absorbing the phosphorus from the food you eat |  |
| Sodium bicarbonate  |                           | Make blood or urine less acidic                                      |  |
| Vitamin D           |                           | Help with calcium absorption and keeps bones strong and health       |  |



# GLOSSARY



- Adult Nephrologist:** An adult nephrologist is a kidney doctor who treats adults.
- Artery:** Arteries take blood from your heart to the rest of your body.
- Acidosis:** A condition where your body has too much acid built up. It can cause tiredness, headaches, and slow your growth!
- Belly Dialysis:** Also known as peritoneal dialysis - a machine pumps fluid into your stomach that cleans the blood from there. You don't have to take blood out of your body with this kind of dialysis.
- Blood Dialysis:** Also known as hemodialysis - a machine takes blood out of your body, cleans it, and then returns it to your body.
- Blood Pressure:** How hard your heart pumps blood to the rest of your body. It has two numbers, systolic and diastolic. Systolic blood pressure is the highest number, and shows how hard the heart can pump blood. Diastolic pressure is the smaller number, and it shows the pressure there is when your heart is at rest.
- Consent Form:** When you sign a consent form, you give your permission for your medical records to be transferred to a new doctor.
- Dialysis:** A machine that helps your kidneys clean your blood when they are too sick to clean your blood by themselves.
- Dosage:** The dosage of your medicine tells you how much to take at one time, and how many times per day you should take the medicine.
- Employer:** An employer is the person that you work for.
- Food Label:** A food label can be found on all packaged foods. The label tells you how much you should eat, and how much of different nutrients can be found in the food.
- Hormones:** Hormones are chemicals that act like messengers in the body. After they are made in one part of the body, they go to other parts of the body where they help control how organs work.
- Organ Donor** An organ donor is someone who chooses to give you one of their kidneys.
- Pediatric Nephrologist:** A pediatric nephrologist is a kidney doctor who treats patients who are under 18.
- Phosphorus:** Phosphorus is a nutrient found in many foods. You may need to eat more foods with less phosphorus depending on your doctor's instructions.
- Pill Box:** A pillbox can be used to keep all of your medicines separated by when you take them.



# GLOSSARY



- Potassium:** Potassium is another nutrient that may be in your food. You can look on the ingredient list on your food to see how much you're eating, and your doctor might tell you to eat more or less potassium.
- Prescription:** A prescription is given to you by your doctor, and you can take it to the pharmacy to get new medicines or a refill on your old medicines.
- Problem Solving:** Problem solving is when an issue comes up and you figure out a way to fix it.
- Renal:** Means something that has to do with the kidneys (ex. Renal disease, renal failure).
- Saturated fat:** Saturated fat comes from the food you eat. If you eat too much saturated fat, it can be bad for your health. You can keep track of how much saturated fat you are eating by checking the nutrition label on your food.
- Self-Advocacy:** Self-advocacy is when you speak up to make sure that your needs are being met.
- Self-Determination:** Self-determination is taking control of your own life and future.
- Self-Management:** Self-management means that you are taking care of your CKD on your own. Once you can self-manage your CKD, you won't need other people to remind you what you need to do to stay healthy.
- Serving Size:** The serving size tells you how much of a food you should eat at once.
- Sodium:** Sodium is also known as salt. You can figure out how much sodium is in your food by looking at your nutrition label. Check with your doctor to know if you should be controlling how much sodium is in your diet.
- Strategies:** A strategy is a way that you choose to approach a problem. For example, if you can't remember when to take your medicines, a strategy can be to use a pill box or alarm.
- Symptom:** The things you feel in your body when you are sick. Examples could be fever, headache, tiredness, and having a hard time focusing on things.
- Transition:** In healthcare, transition is the move from a pediatric doctor to an adult one, and learning to manage your disease on your own.
- Transplant:** Transplant is when your kidneys stop working and you get a new kidney from a donor.
- Vein:** Veins move blood from your body and take it back to the heart.