



Transplant
UNWRAPPED
Kids

**SHORT BOWEL
SYNDROME AND
INTESTINAL
REHABILITATION**

**An Activity Book for Kids
Going Through
Intestinal Rehab**

My Very Own Intestinal Activity Book

My name is _____.

I am _____ years old.

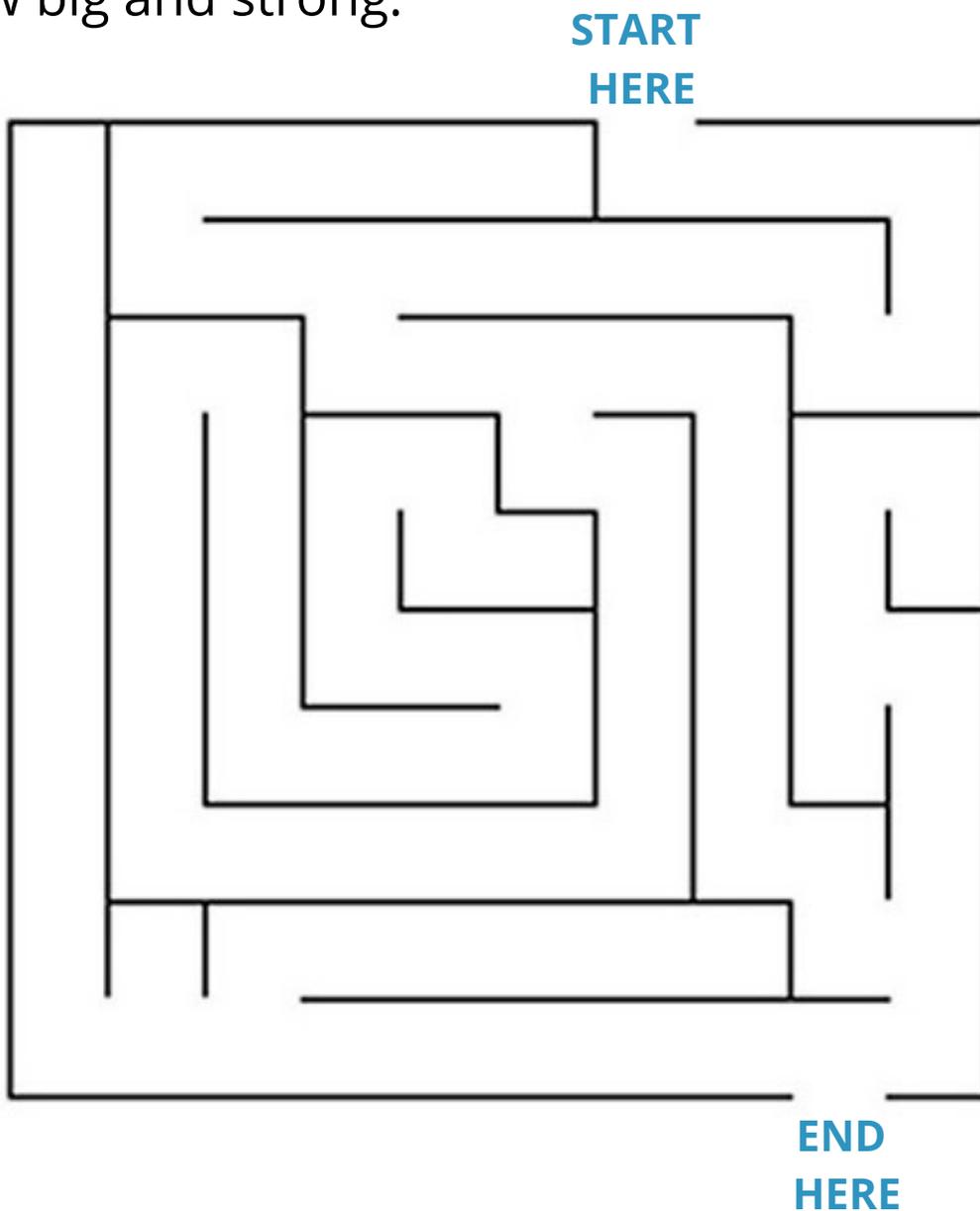
I was born on _____ (month) _____ (day) _____ (year).

Here is a picture of my family and I. (Either draw a picture or glue in a photo taken)

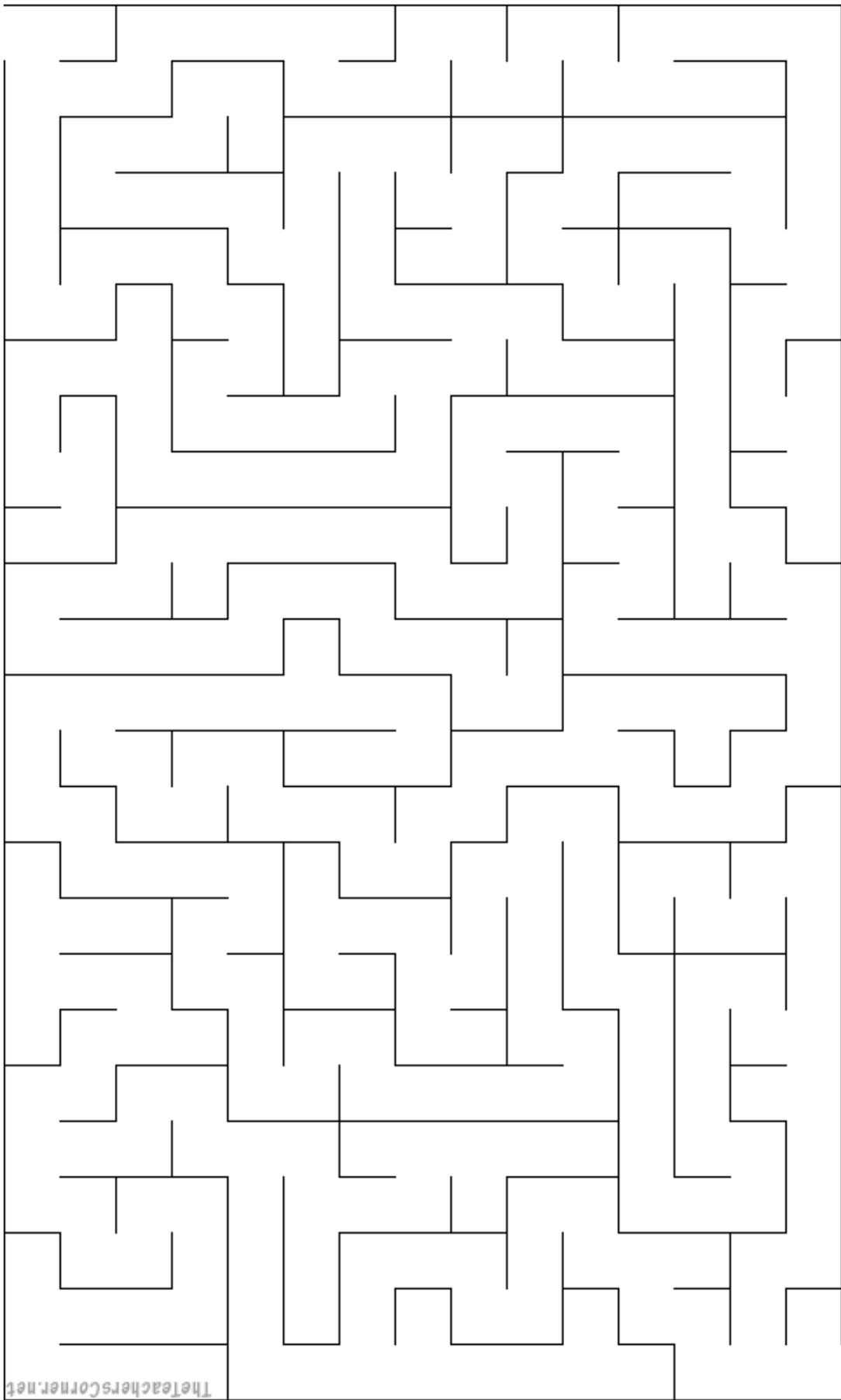
Usually the small intestine is long and windy, like the maze on the next page, but...

When you were born, your doctor told your parents that your intestine, the part inside your belly that helps to absorb the food and drink you consume, was too short, like the short maze below. This is known as **short bowel syndrome (SBS)**.

This means you cannot eat enough by mouth to be able to grow big and strong.



START
HERE



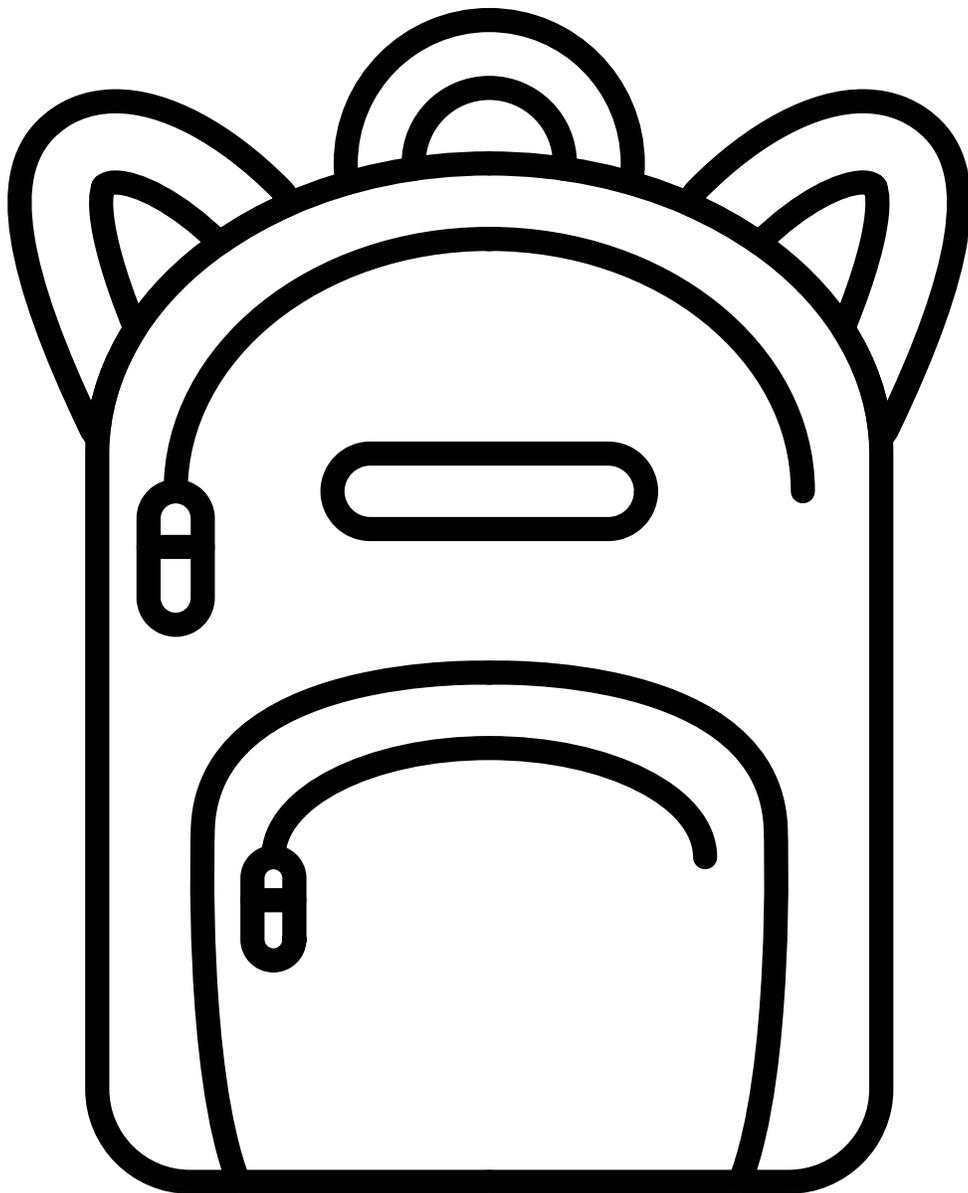
END
HERE

Fun Fact! Unless you have short bowel, most people's small intestine grows to be 23 feet long. That is a lot of gut!

If you cannot eat enough by mouth, you may need to get nutrients through your veins. This is called **parenteral nutrition** or PN.

Other kids may get nutrition through a special tube in their stomach or intestine. This is called **tube feeding** or **enteral nutrition**.

Most kids put their TPN or tube feeds in a backpack. If your backpack could look as cool as you wanted, what would the design be? Show the design below!



Enteral Nutrition

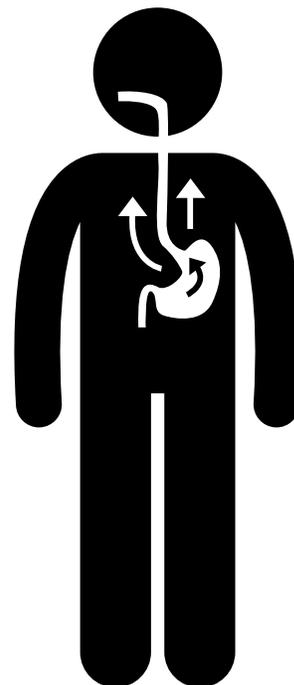
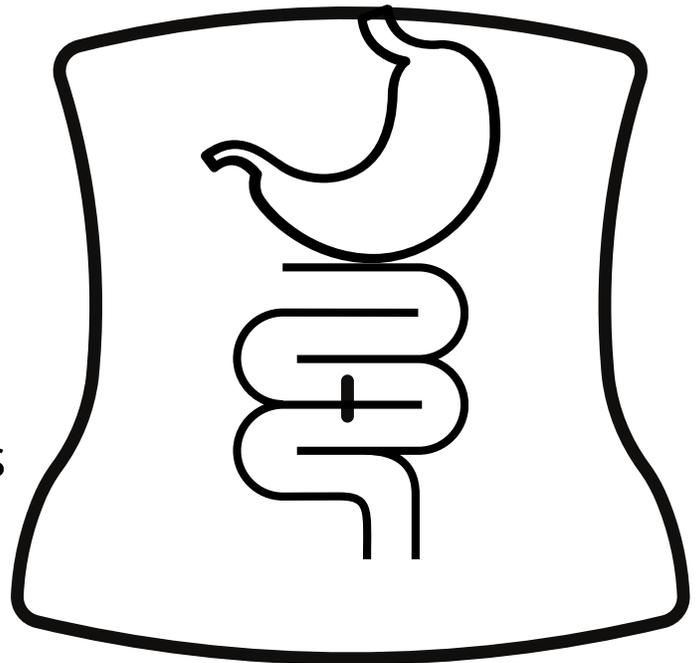
If you cannot eat enough by mouth, your doctor may suggest getting a small tube placed in your belly so special formula can be given via the tube directly into your stomach or intestine.

Draw the type of tube you have on the figure:

A **G-Tube** is when the tube goes into your stomach.

A **J-Tube** is when the tube goes into the second part of your small intestine called the jejunum.

Sometimes you may have a temporary tube. This is called an **NG-Tube**. It is when the tube goes from your nose into your stomach.



Your **parenteral nutrition (PN)** must go into your body through a special line in your chest, known as a **central venous catheter**.

It is very important to keep your special line very clean to avoid getting any infection that could make you very sick.

One of the most important ways to keep yourself healthy is to wash your hands.

Color the steps to good hand washing.



1. Wet your hands before applying soap.



2. Rub soap all over your palms, the backs of your hands, and in between your fingers.



3. Wipe your hands with a clean towel or paper towel.

How long should you wash? Wash for 20 seconds. You can sing your ABCs or sing Happy Birthday two times!

Your doctors want to try and help you get off of PN or tube feeds and be able to eat and drink enough on your own to be able to grow like other kids.

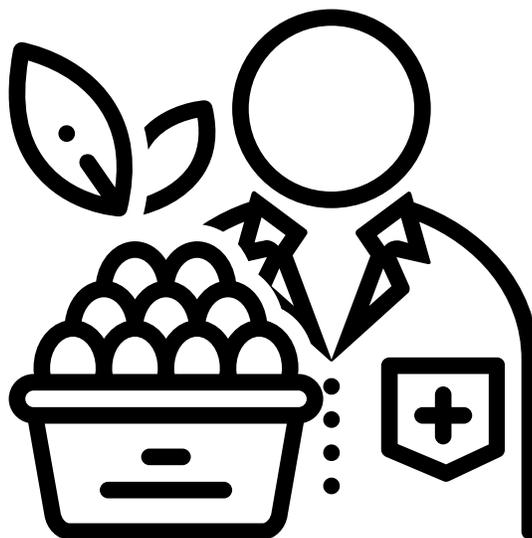
A normal-length small intestine helps break down the food you eat, absorbs it, or takes it in, so your body can use it to grow strong and healthy. Since your intestine is too short, it is not able to do this like normal.

Because of this, your doctor and other team members may tell you and your parents about different treatment options, **such as intestinal rehabilitation**, to help you get off of PN or tube feeds and begin to eat on your own.

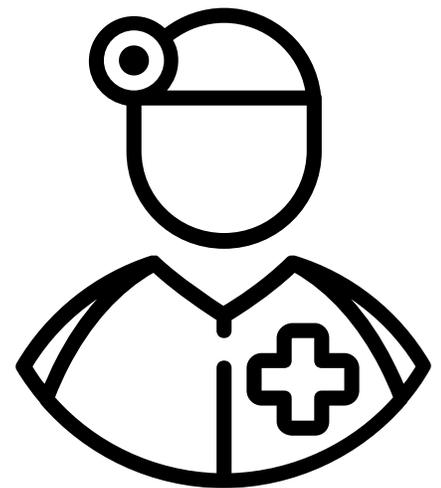
Some Members of My Intestinal Rehab Team



Gastroenterologist



Dietician



Surgeon

Finding the Best Foods For You

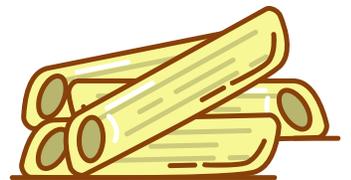
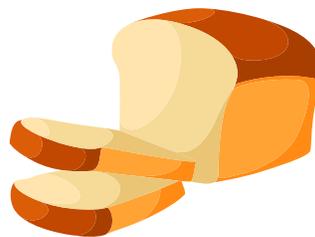
The first part of intestinal rehabilitation is finding the best foods for you. There are three major food groups you need to have in your diet to grow strong and healthy.

The first food group is called **carbohydrates**. They are an important energy source for your body. Carbohydrates are found in nearly every food you eat. **There are two types of carbohydrates:**

1. **Simple carbohydrates:** This is what you know as sugar, like what you see in your sugar bowl or the sweetness when you lick a lollipop.

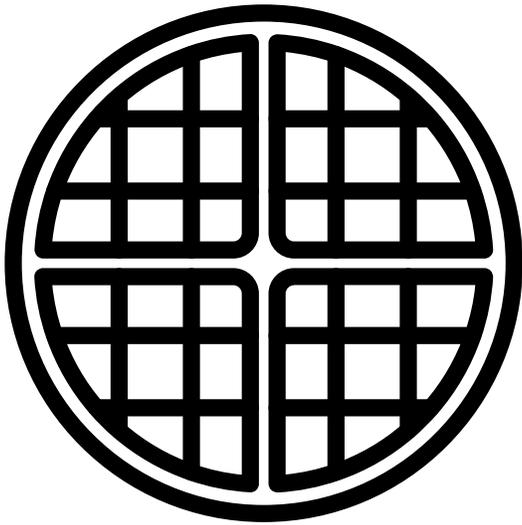


2. **Complex carbohydrates:** These are known as starches. Examples include bread and pasta.

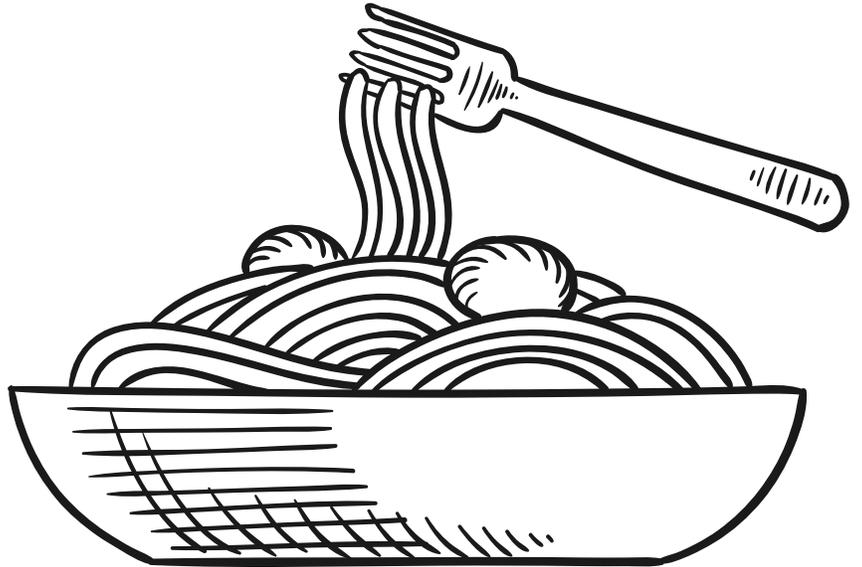


When you have a short bowel you need to **avoid** simple carbohydrates (sugars) because this can make your diarrhea worse. The more diarrhea you have, the more likely you might become dehydrated or sick.

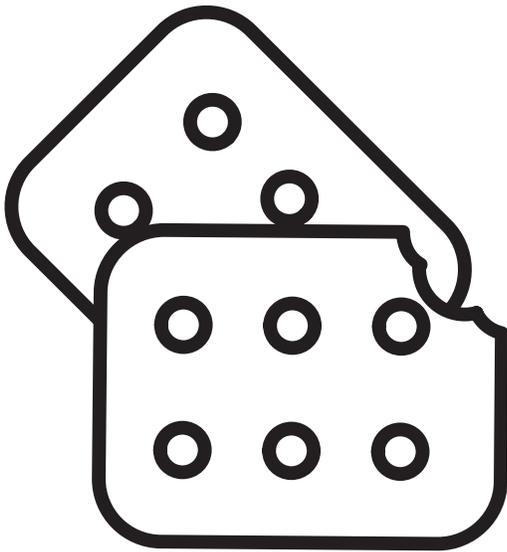
Color these ideas of complex carbohydrates you can **include in your diet**. Add any other foods your dietician suggests that may fall into this category.



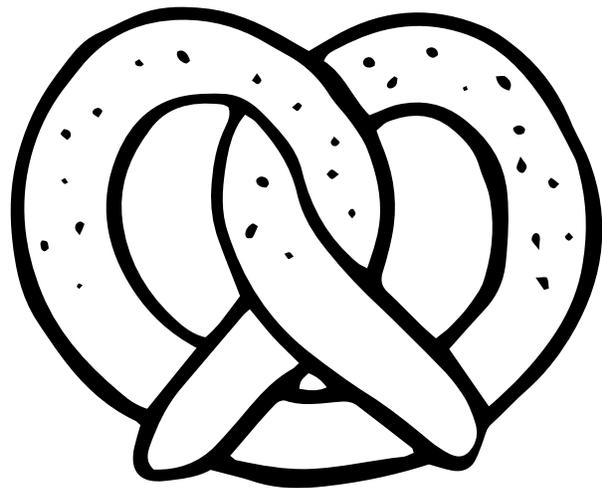
Plain waffle



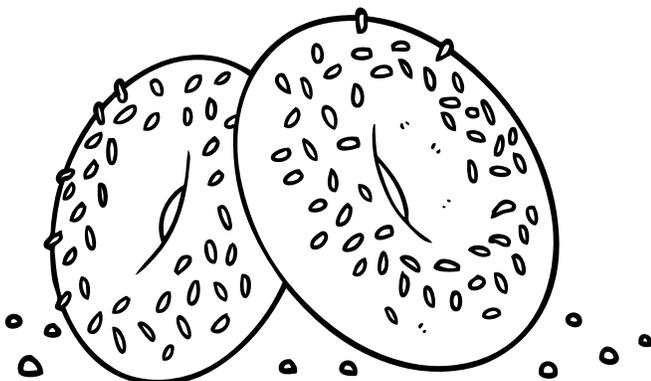
Pasta



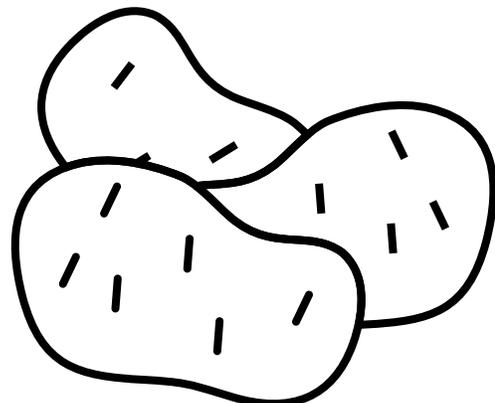
Crackers



Pretzels

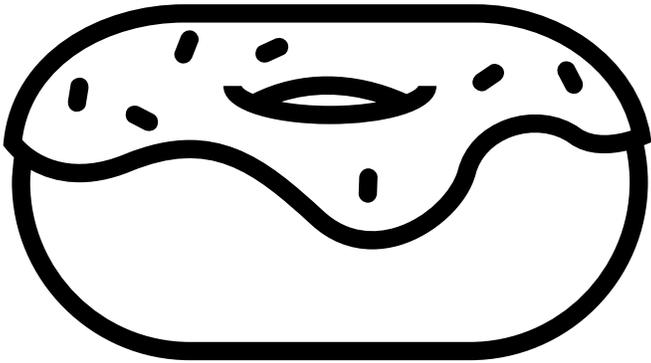


Bagels

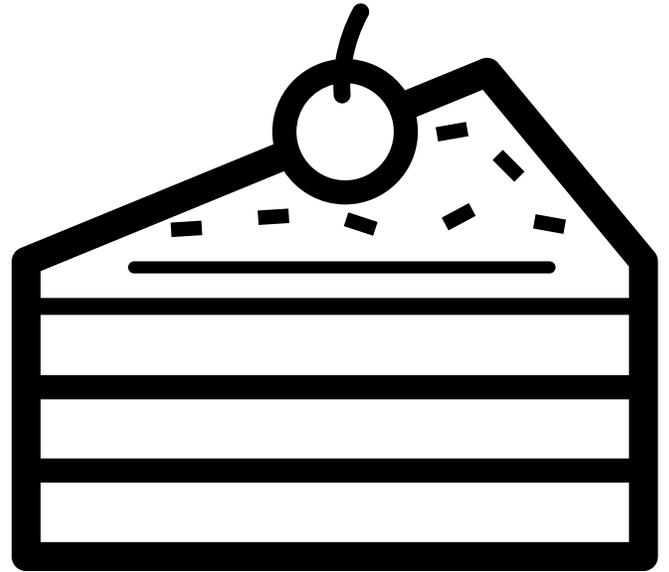


Potatos

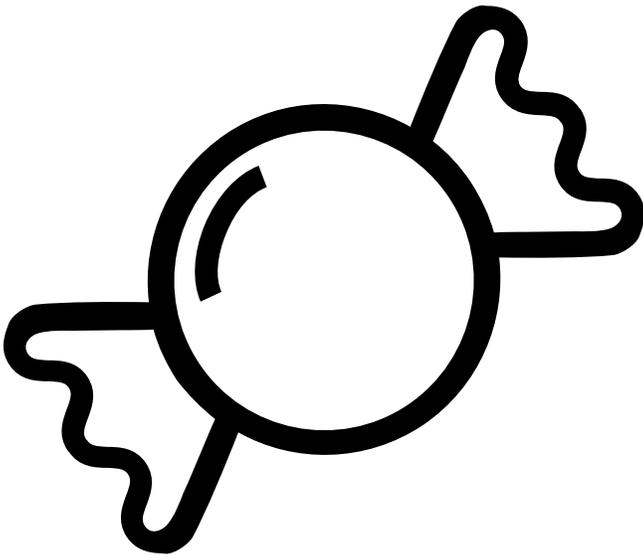
Color these ideas of simple carbohydrates **to avoid**. Add any other foods your dietician suggests that may fall into this category.



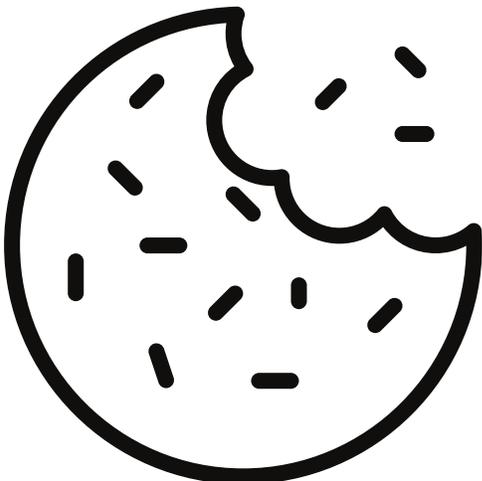
Doughnut



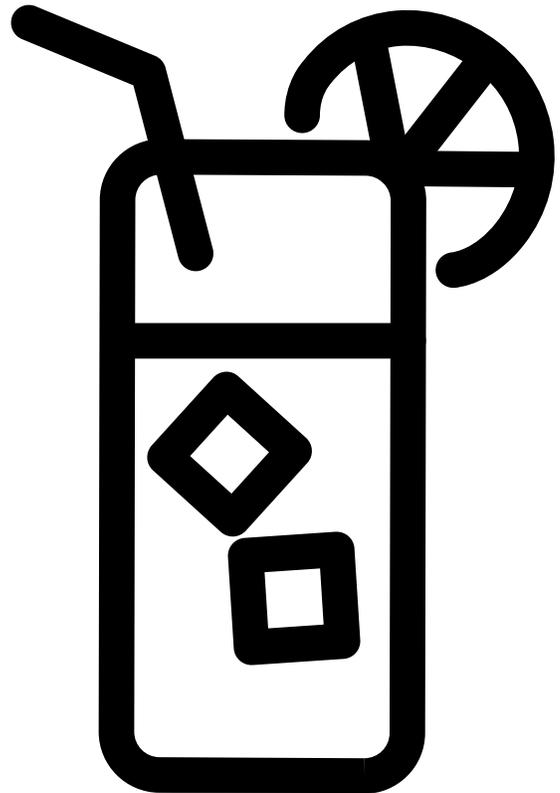
Cake



Candy



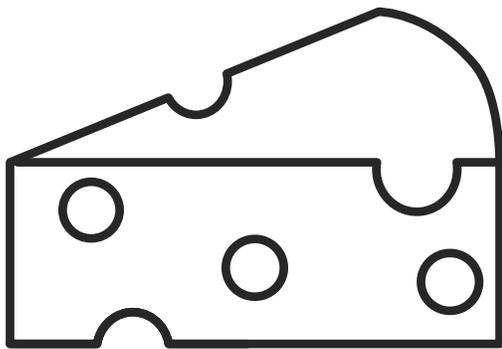
Cookie



Sugary drinks and juices

The next important food group is known as **protein**. Protein is very important in building, repairing, and maintaining all the tissues in your body.

Color these good sources of protein:



Cheese

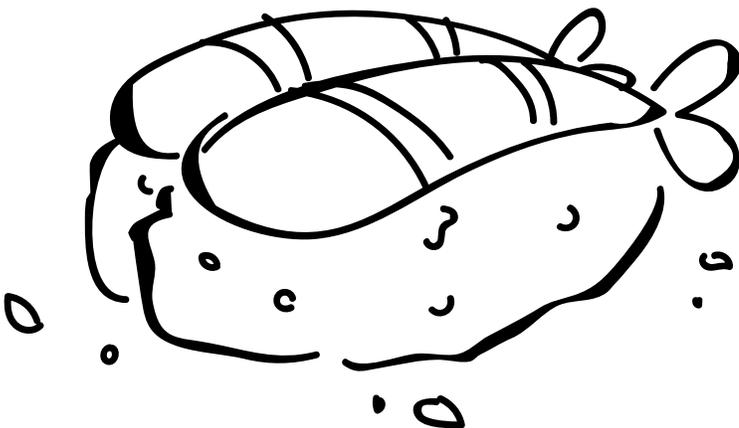


**Unsweetened
Yogurt**

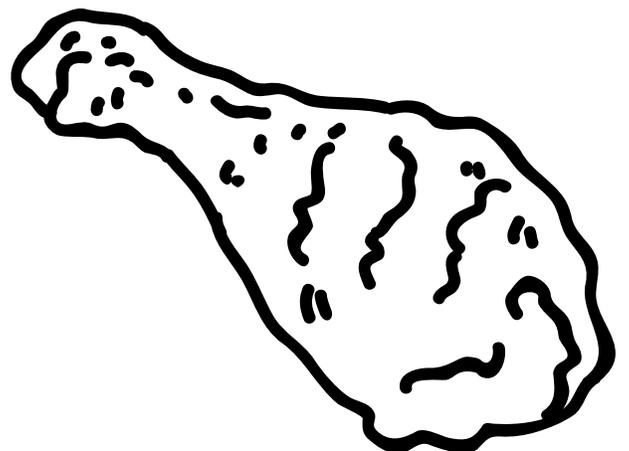


**Chicken
Breast**

Avoid these sources of protein:



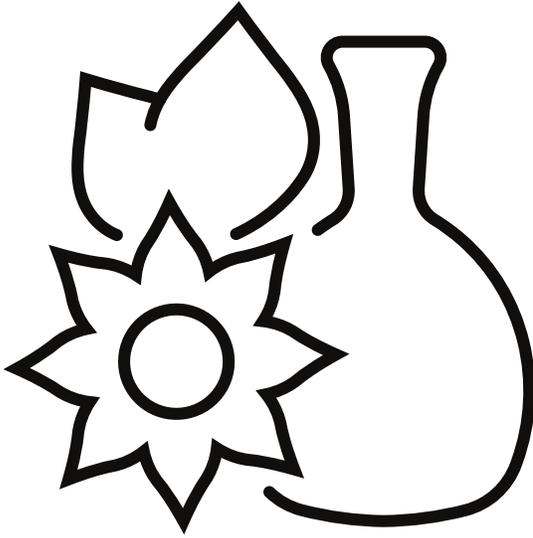
Raw Fish



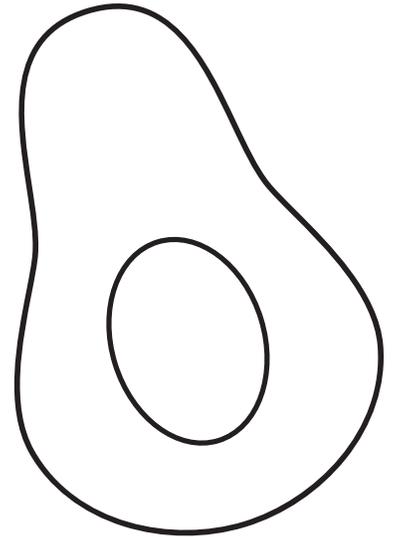
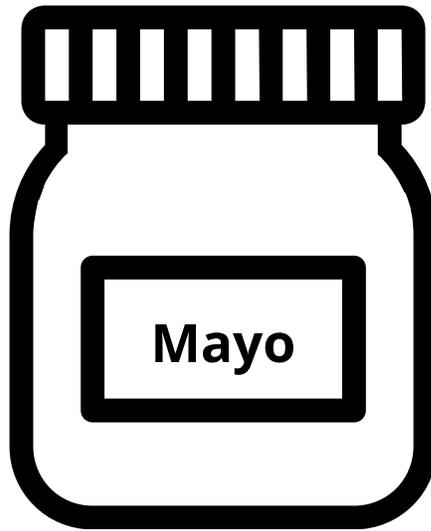
Fried Chicken

The last important food group is known as **fat**. Fat is a great source of energy and gives us essential fatty acids that our body cannot make.

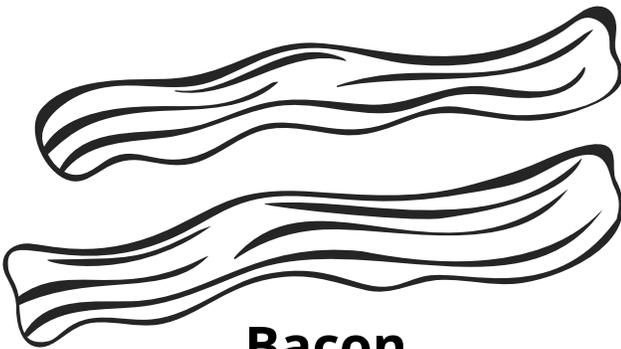
Color these good sources of fat:



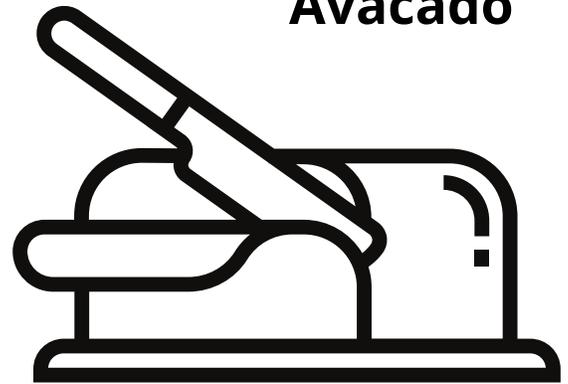
Sunflower Oil



Avacado



Bacon



Margarine

Avoid these sources of fat:



**Cream,
Half and
Half**



**Sweetened
Cream
Cheese**

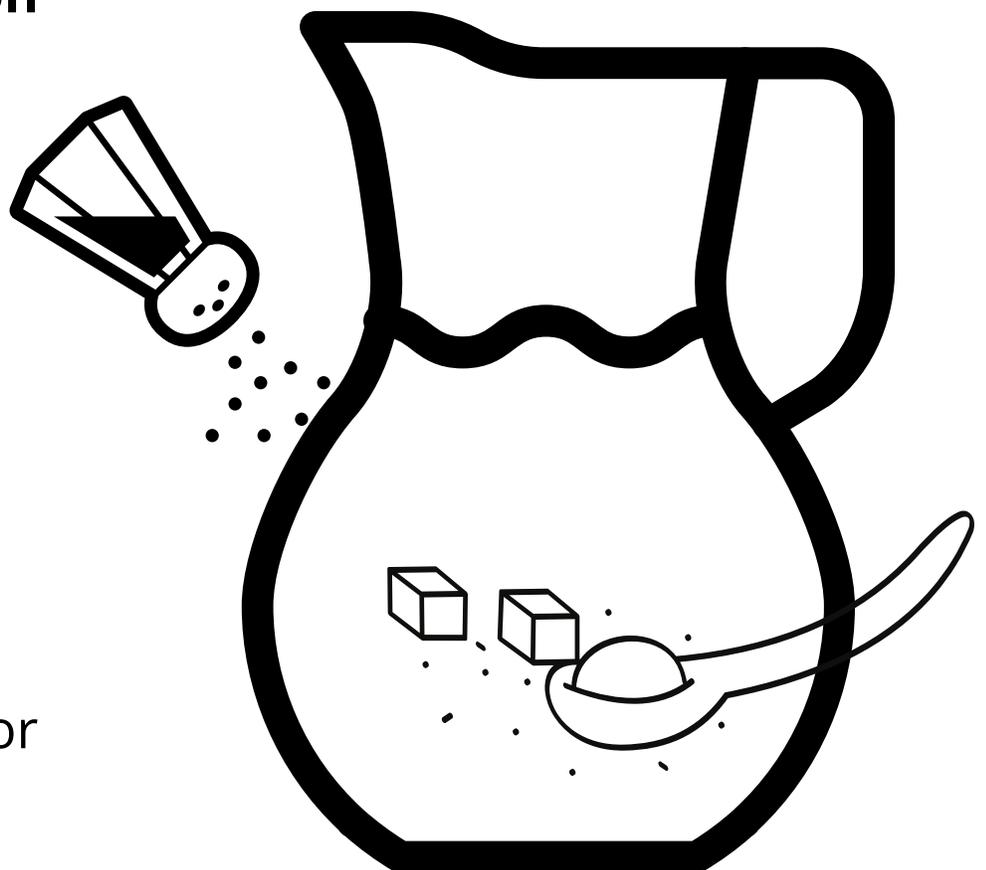
The next important step of intestinal rehab is making sure you get enough fluid to keep your body hydrated. Your doctor or nutritionist will help you find drinks to keep you hydrated.

Remember, drinks **high in sugar** will cause your **diarrhea to get worse** because more water gets pulled into your intestine.

To stop this from happening there are special drinks known as **oral rehydration solutions (ORS)**. Your parents can buy these for you at the store, such as Pedialyte ®, or you can make your own at home. **Color your homemade oral rehydration solution (ORS).**

Oral Rehydration Recipe

1. Quart of Water
2. 3/4 tsp. salt
3. 2 tbsp. sugar
4. Sugar-free drink mix, like Kool-Aid for taste



Complete this fun word search with important
intestinal rehab terms.

G Z H R P E J S N H F D V B D
N I W Y Y J D U R U S M Y S N
T D Q B D V W G Q V A C G P C
D E H D M R M A M R L A A R U
I N Z U T H A R S M T R T O F
A T O X Q E U T T P N B T T C
R E M I Q A F S I X O O E E M
R R V P N B W I L O P H X I G
H A K I F T Z H B I N Y T N B
E L N F T J E K F E H D T T O
A N J J Q A P S H A R R L H B
P B R P D K M Q T M T A I H Y
O Y P Y U G I I U I Y T H W H
Z B O T K A X G N G N E N S M
P T E O G X Y H N O W E Q O Y

Word List

Carbohydrate	Intestine	Hydration	Enteral
Vitamin	Gattex®	Protein	Fiber
Sugar	Fat	Diarrhea	Salt

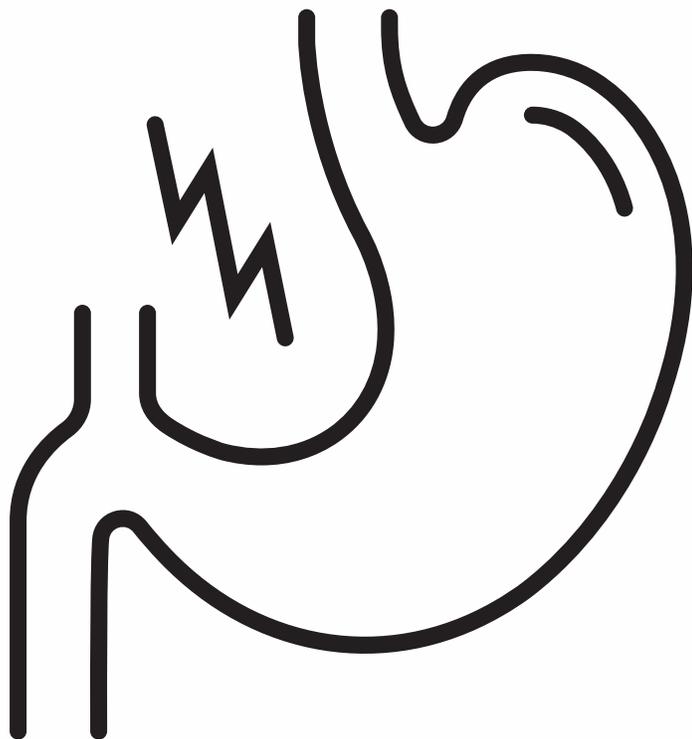
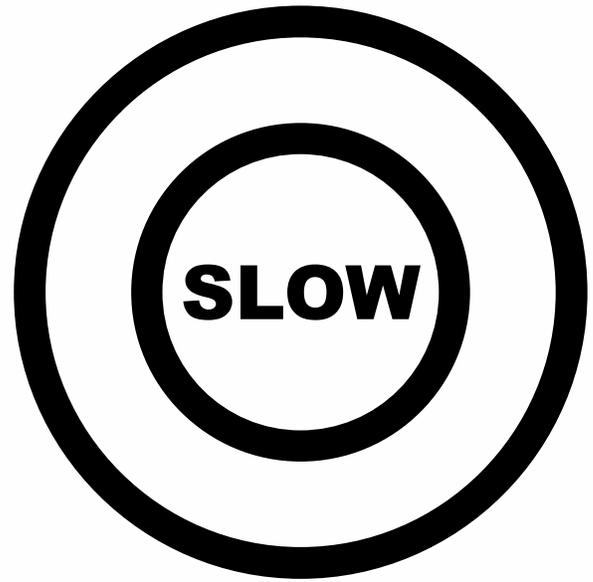
Answer Key

G Z H R P E J S N H F D V B D
N I W Y Y J D U R U S M Y S N
T D Q B D V W G Q V A C G P C
D E H D M R M A M R L A A R U
I N Z U T H A R S M T R T O F
A T O X Q E U T T P N B T T C
R E M I O A F S I X O O E E M
R R V P N B W I L O P H X I G
H A K I F T Z H B I N Y T N B
E L N F T J E K F E H D T T O
A N J J Q A P S H A R R L H B
P B R P D K M O T M T A I H Y
O Y P Y U G I I U I Y T H W H
Z B O T K A X G N G N E N S M
P T E O G X Y H N O W E Q O Y

Your doctor may recommend you take some medicines that will help you absorb your food and fluids better.

There are many types of medicines that your doctor may use. **Color the corresponding pictures.**

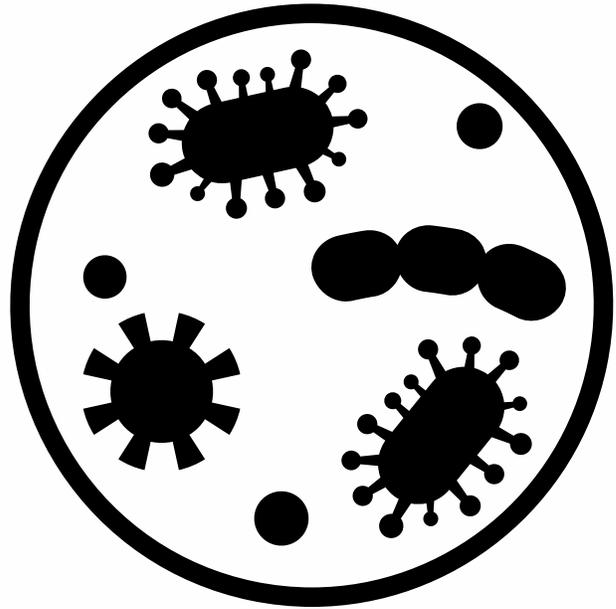
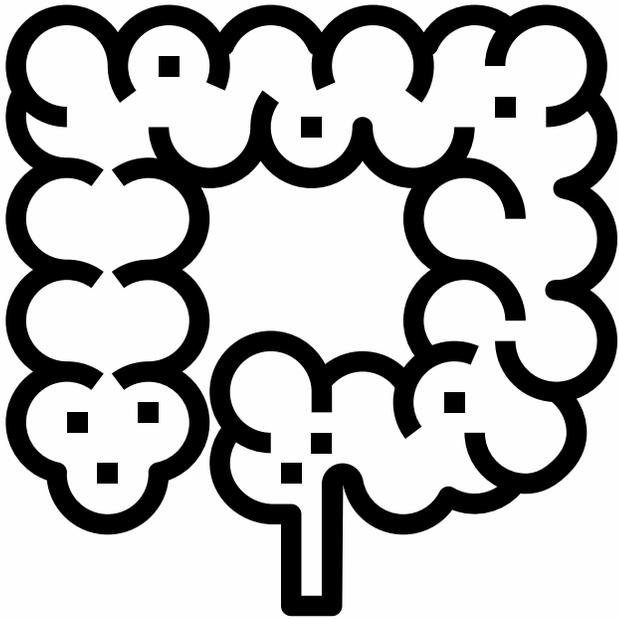
One type is are **anti-diarrheal medications**. These medicines slow down the food moving through your intestine, so there is more time for your intestine to absorb the nutrients you need.



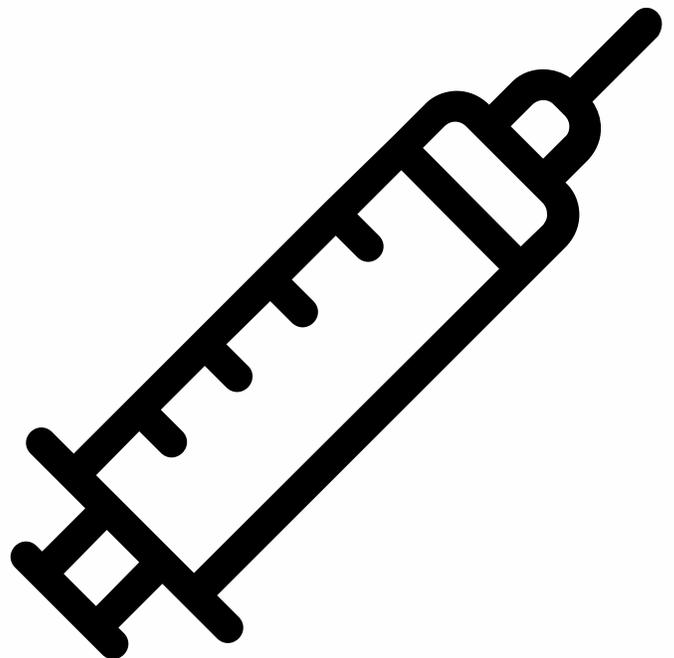
Your doctor may prescribe medications that help to **decrease the acid in your stomach**. These might help you feel better, especially if you ever feel burning in your chest (known as heartburn).



Sometimes when you have a short bowel, the bacteria in your intestine will grow too much. This is called **bacterial overgrowth**. Your doctor may give you an **antibiotic** to help get your bacteria back in balance.

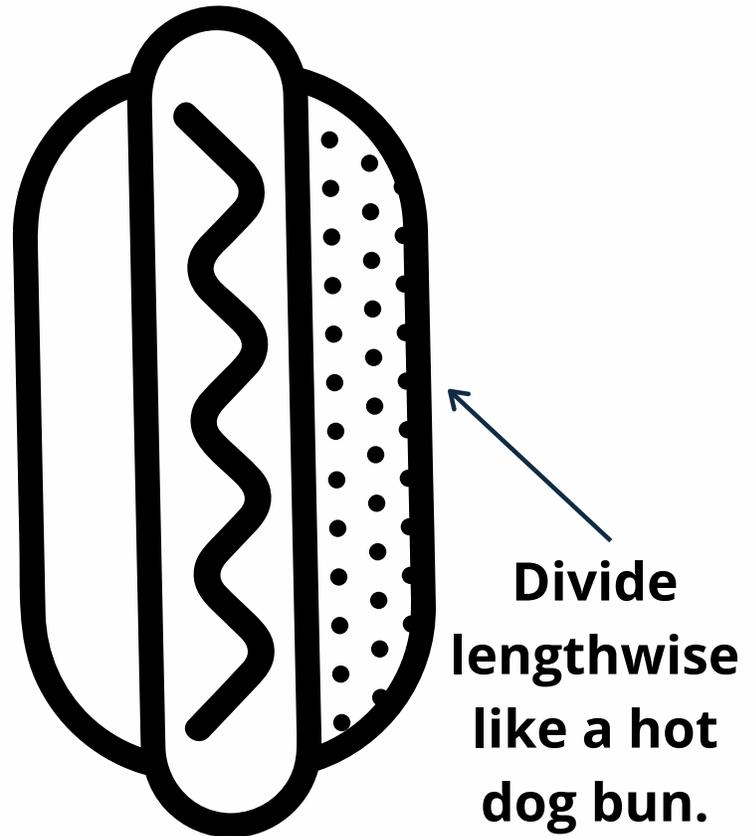


To help your intestine adapt and absorb more nutrients, your doctors may suggest a special medication known as **Glucagon-Like Peptide-2 (GLP-2) (Teduglutide, Gattex®)**. This comes as an injection, but don't worry, it will only sting for a second!

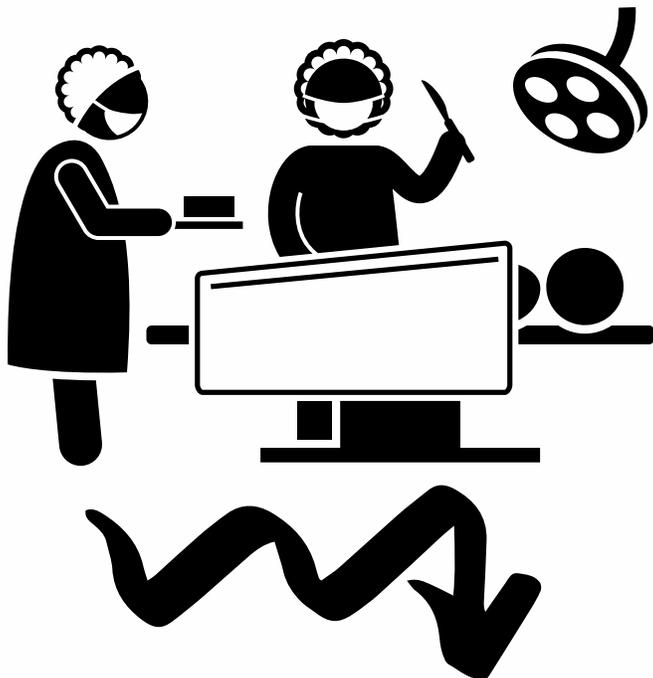


The last option for **intestinal rehab is surgery**. Your doctor may suggest an operation that uses your own intestine to help it become longer and be able to absorb more nutrients.

Bianchi Procedure: This is a procedure where your doctor goes into your belly and divides your intestine lengthwise (i.e. hot dog bun style). It is then sewed back together, essentially doubling the length of your bowel. This helps you absorb more nutrients.



Serial Transverse Enteroplasty (STEP): During this procedure, your doctor will go into your belly and make tiny cuts in your intestine in a zig-zag pattern. This makes your intestine longer and helps you absorb more nutrients.



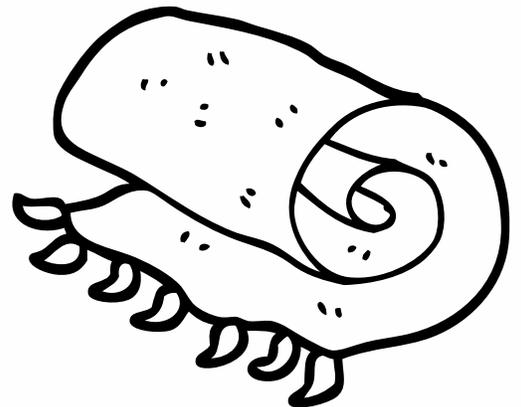
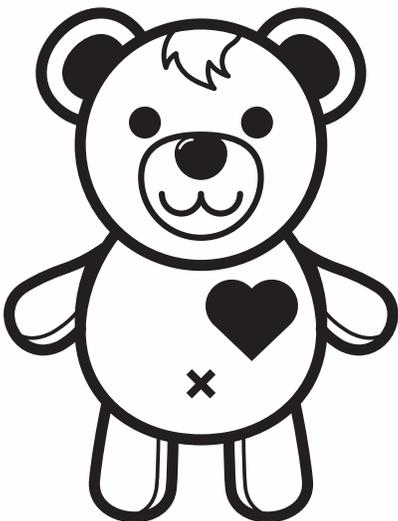
Are you nervous about an upcoming surgery? Join Max from Transplant Unwrapped Kid's and watch the ["Preparing for Surgery" video](#).

Preparing for Surgery

You may be nervous to go into surgery, but remember your whole team is there to make sure everything goes smoothly and makes sure you are comfortable.

Before going to the hospital for surgery, be sure to pack some of your favorite things, such as a stuffed animal or special blanket.

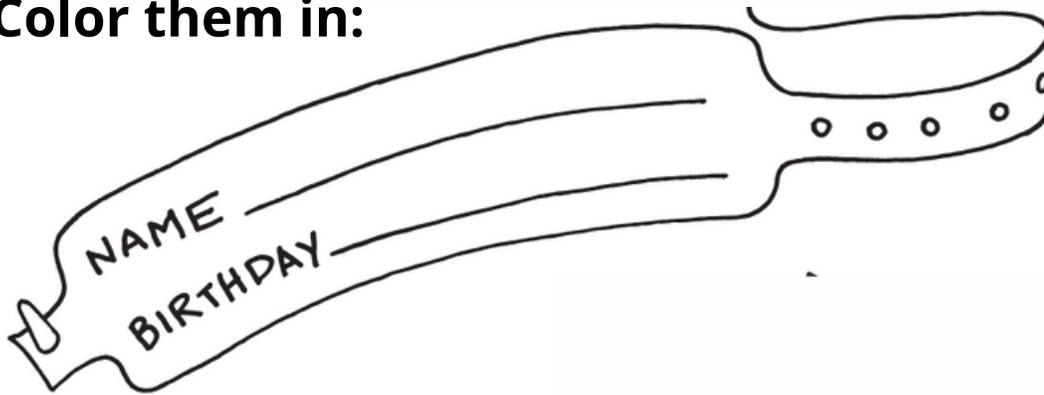
Draw what will you bring with you to the hospital.



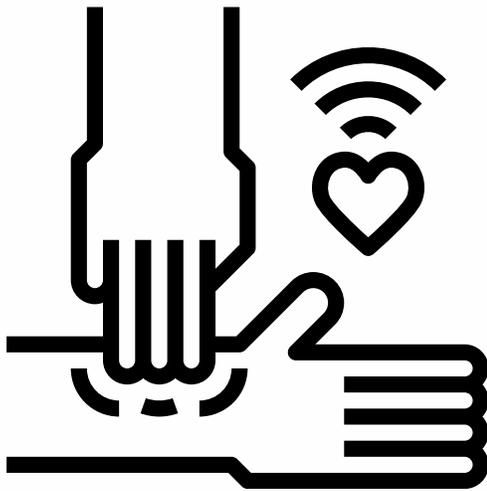
Preparing for Surgery

When you get to the hospital, the nurses will prepare you for surgery. There are many things you should expect.

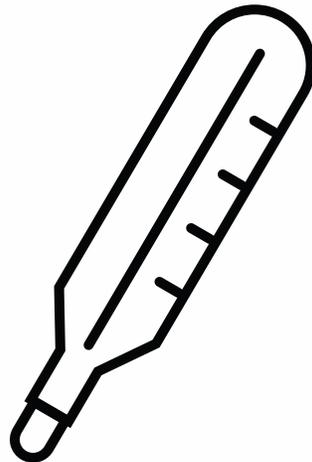
Color them in:



Fill out your wristband like the one you are going to get.



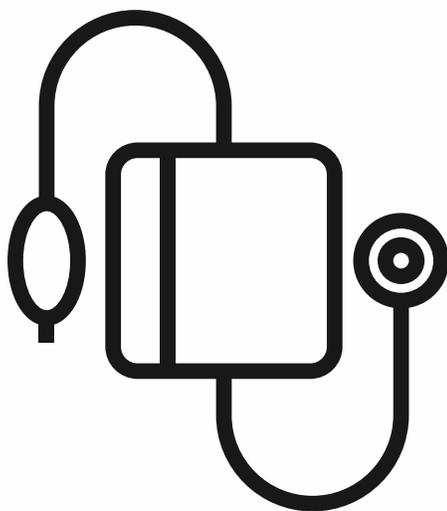
**Pulse or
Heart Rate**



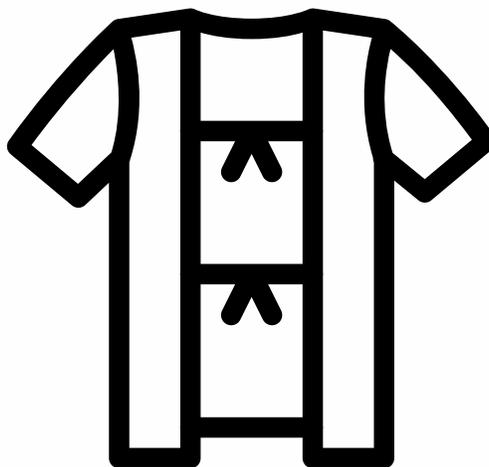
Temperature



Weight



Blood Pressure



**Hospital gown, like
special pajamas.**



**Heart and lungs
check.**

Preparing for Surgery

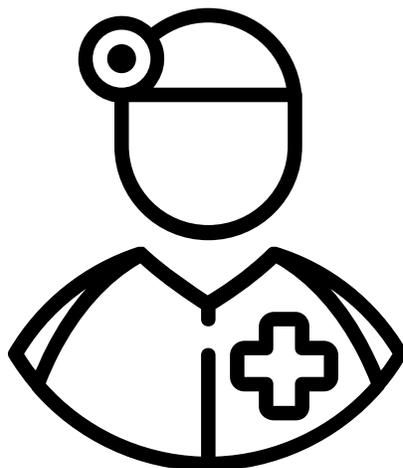
What happens when I am prepped and ready to go?

- When it is time to go have your procedure, you will be able to say "see you soon" to your family and then the team will wheel you into the operating room.
- The special doctor will give you a medicine called anesthesia that will make you sleepy and you will peacefully fall asleep.
- You will stay asleep the whole operation and you will not feel, hear, or see anything.

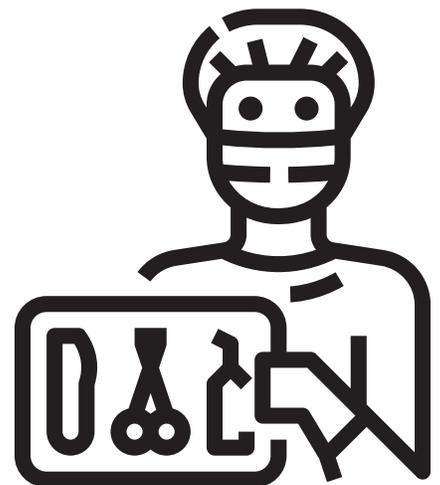
Some Team Members in the Operating Room (OR)



Nurse



Anesthesiologist

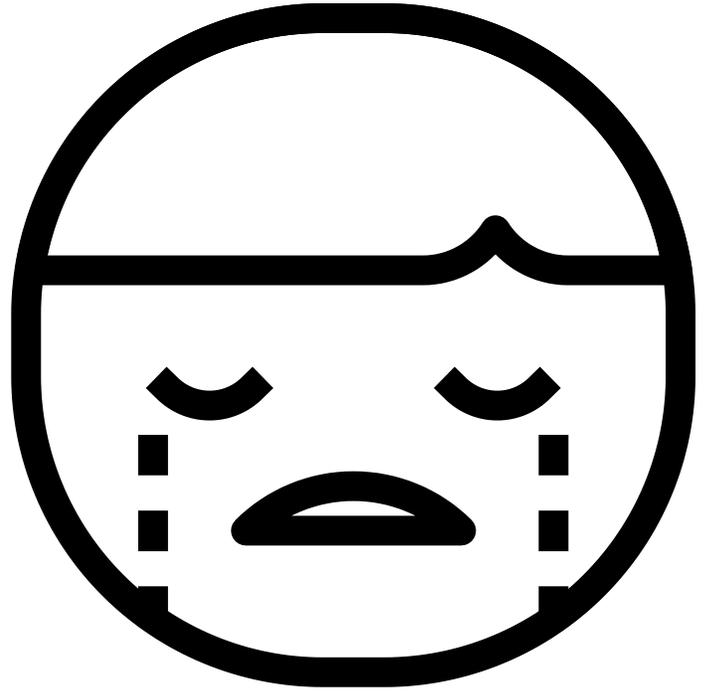


Surgeon

After Surgery

When you wake up you may also have some pain. If you do, tell the nurse and they can give you some medicine to make you feel better.

Color these faces. After surgery, you can point to the face to tell the nurse how you are feeling.

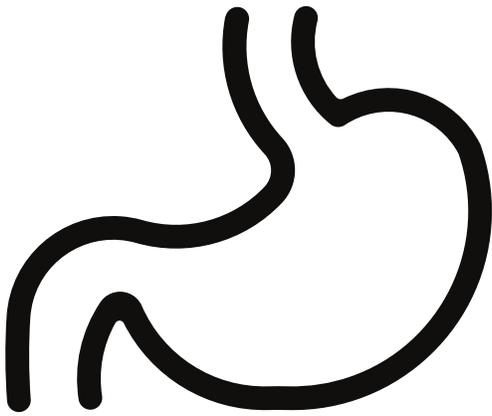


Organ Transplant

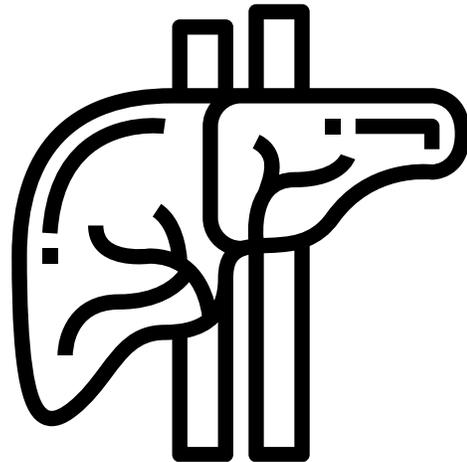
If PN starts to cause you problems and the doctor decides they have tried to help you in all other ways, they may evaluate you for an intestinal or multivisceral transplant.

An intestinal transplant is when doctors replace an unhealthy old intestine with a healthy new intestine. Your doctor may decide to include other organs inside your belly too.

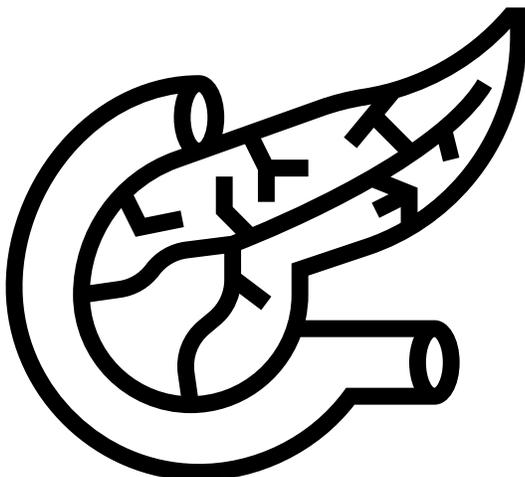
Circle and color the organs your doctor is going to replace.



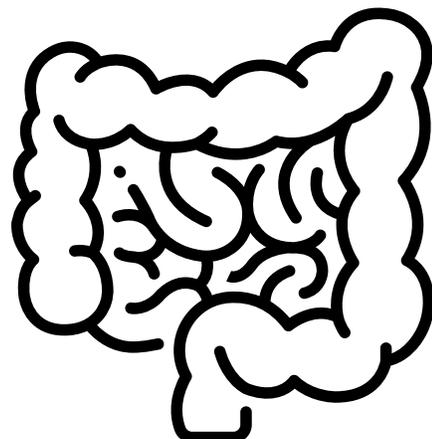
Stomach



Liver



Pancreas



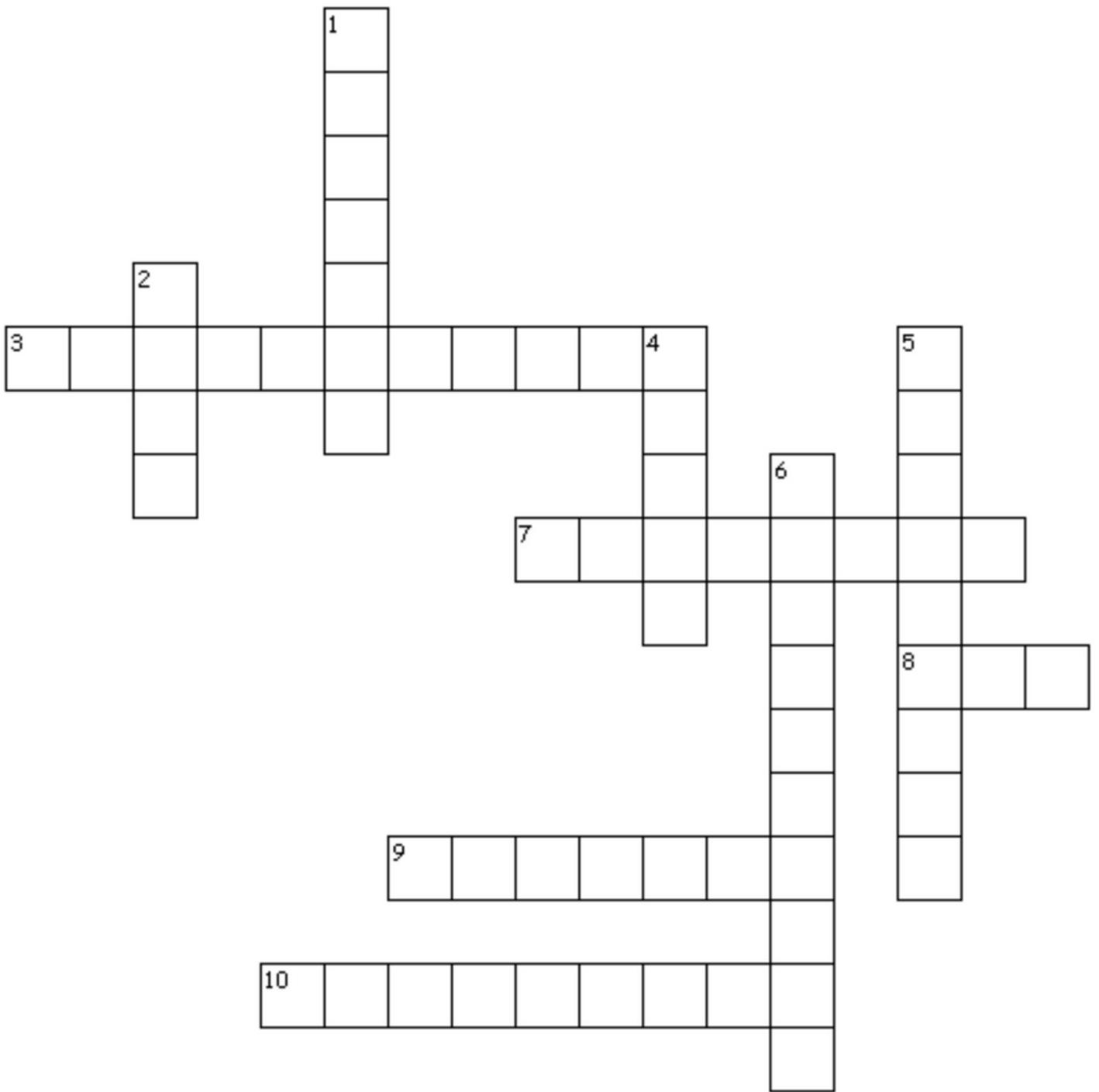
Intestine

Once you are feeling better you will be able to start playing with your friends again and becoming more active.

Hooray! You have made it through the hardest part of the journey.

Draw your favorite activities with friends.





Intestinal Rehabilitation Crossword

Clues on the Next Page



Intestinal Rehabilitation Crossword Clues

Across

3. These are given when you have too much bacteria in your intestine.
7. When your poop is really soft or watery.
8. This is nutrition that goes directly into your veins when you cannot absorb enough food by mouth.
9. This is when you receive your nutrition through a tube in your belly, known as a G-tube or J-tube.
10. This is a member of your team that helps you find the best food and drinks for you to help you grow strong.

Down

1. This is an important nutrient that helps to build, repair, and maintain the tissues in your body.
2. This is a procedure that makes zig-zag cuts in your intestine to make it longer.
4. As a short bowel patient you should avoid this type of carbohydrate in your diet because it can increase diarrhea.
5. The organ in your body that is a long tube that breaks down the food you eat and turns it into energy for your body.
6. This is when your unhealthy organs are replaced by healthy organs.

Intestinal Rehabilitation Crossword Answers

Across

3. These are given when you have too much bacteria in your intestine.

Antibiotics

7. When your poop is really soft or watery. **Diarrhea**

8. This is nutrition that goes directly into your veins when you cannot absorb enough food by mouth. **TPN**

9. This is when you receive your nutrition through a tube in your belly, known as a G-tube or J-tube. **Enteral**

10. This is a member of your team that helps you find the best food and drinks for you to help you grow strong. **Dietician**

Down

1. This is an important nutrient that helps to build, repair, and maintain the tissues in your body. **Protein**

2. This is a procedure that makes zig-zag cuts in your intestine to make it longer. **STEP**

4. As a short bowel patient you should avoid this type of carbohydrate in your diet because it can increase diarrhea. **Sugar**

5. The organ in your body that is a long tube that breaks down the food you eat and turns it into energy for your body. **Intestine**

6. This is when your unhealthy organs are replaced by healthy organs. **Transplant**

More Info? Contact or Visit us.



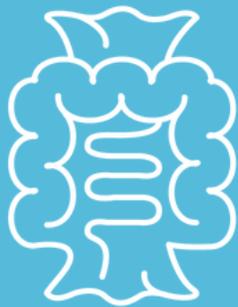
info@transplantunwrapped.org



www.transplantunwrapped.org



www.transplantunwrappedkids.org



Transplant UNWRAPPED

© 2021 Transplant Unwrapped. All rights reserved.

Disclaimer: This booklet is not intended to be used as medical advice or to diagnose, treat, cure or prevent any disease, nor should it be used for therapeutic purposes or as a substitute for a health professional's advice. Transplant Unwrapped does not accept any liability for any injury, loss or damage incurred by use of or reliance on the information presented.