



Transplant
UNWRAPPED
Kids

INTESTINAL TRANSPLANT FOR KIDS

**A Helpful Guide for
Kids Going Through
Intestinal Transplant**

The Basics: Your Digestive System

Fun Fact: In one day, your salivary glands can produce up to six cups of saliva! (1)

When you put food into your **mouth** and chomp down with your teeth, you break the food into smaller pieces. This also causes special structures in your mouth called **salivary glands**, to produce saliva.



Fun Fact: Your stomach can expand to the size of a football with food inside.



Food then moves down a tube in your throat, the **esophagus**, and enters your stomach. This only takes about 7 seconds! (2)



The **stomach** is a stretchy muscular sack that releases digestive juices and acid to help breakdown food. The muscular contractions of the stomach, known as peristalsis, pushes the food out of your stomach and into your small intestine.



The Basics: Your Digestive System

Fun Fact: In the average adult the small intestine is 20 ft. and large intestine is 5 ft.

The **small intestine** breaks down your food more, allowing the nutrients to pass through the small intestine's lining. This gives your body the fuel it needs to grow strong and healthy.



Fun Fact: Poo smells because of the bacteria in your gut and the chemicals they release.

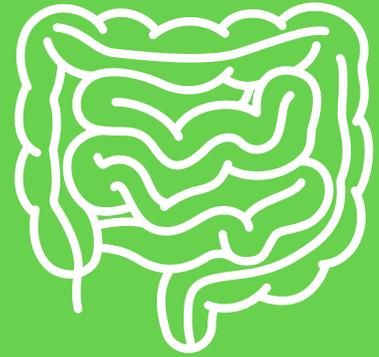
The mush that is left then moves to the last portion of the digestive tract known as the large intestine. The large intestine helps to absorb any water or minerals that may have been left-over. The remaining substances is known as feces, or poop!

When you feel like you need to go to the restroom, a ring of muscle called the anus relaxes to allow the poop to come out!



How does the digestive system relate to intestinal transplant?

Sometimes kids are born with not enough small intestine, which is known as **short bowel syndrome**. In other instances, sometimes the small intestine you do have doesn't work.



When this happens, the intestine is **not able to absorb** the amount of food and fuel you need to keep you healthy and growing. This means that you will need to have **nutrition in your veins** through a special line placed in your chest. This is called **parental nutrition (PN)**.



Why can't I stay on PN forever?

- **PN** helps your body get the food and nutrients it needs, but it can also cause problems and be difficult for your body to handle.
- PN can sometimes lead to **serious infections**, **blood clots**, or it can cause **damage** to your **liver**, which is another important organ in your digestive system.

What is an intestinal transplant?

An intestinal transplant is an operation where doctors put a new intestine in the body of someone whose own intestine is no longer working.

When might my doctor recommend an intestinal transplant?

First, your doctor determines if you have a condition that makes it, so you cannot **eat enough food by mouth** to grow and get the right nutrients your body needs.

When your body is not able to **absorb enough** of your nutrients, this is called **intestinal failure**. Most kids with intestinal failure have to be on parenteral nutrition; however, if PN starts to cause you problems, your care team **may recommend an intestinal or multivisceral transplant**.

Transplant Evaluation

If your doctor recommends you for an intestinal transplant, you first have **many tests and appointments** to make sure that it is the right choice for you.

These **may seem scary** and overwhelming, but the whole transplant team is there for you and wants to **help** you.

Transplant Team Members



Transplant Surgeon:

This is the doctor that will do the operation on your tummy.



Gastroenterologist:

A doctor that helps take care of your tummy and helps manage your nutrition.



Transplant Nurse Coordinator:

This is a nurse that will help you through your entire transplant journey. Do not be afraid to ask them any of your questions.



Social Worker:

his person makes sure your family is ready to take care of you before and after your transplant.

Transplant Team Members



Child Life Specialist:

This person makes sure you have a fun and good experience when going through your transplant.



Psychiatrist: This person asks if you are feeling happy or sad. They help you with your emotions.

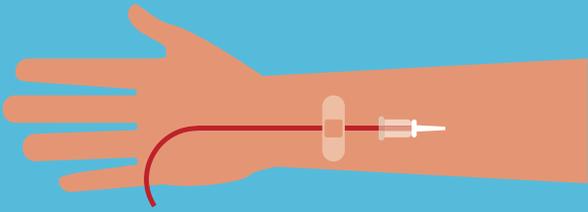


Cardiologist: This doctor checks your heart to make sure it is pumping enough blood throughout your body and is working correctly.



Infectious Disease Doctor: This is a doctor that asks you questions about past fevers, earaches, and sore throats. They are looking for past and current signs of infection.

Possible Evaluation Appointments

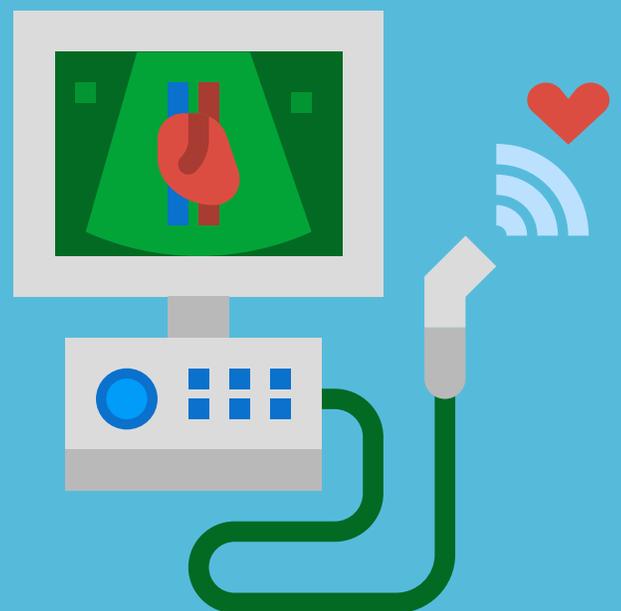


Bloodwork: A small needle will be used to take some blood from the veins on your arm. You will feel a little pinch at the beginning, but after that, it should not hurt.

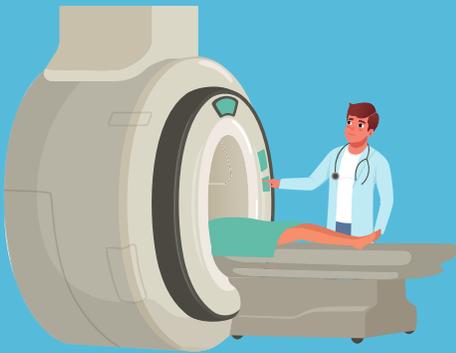
Electrocardiogram (EKG): Sticky pads are placed on your chest, arms, and legs and tells the doctors how well your heart is beating. The test does not hurt.

Echocardiogram: This test uses a wand that moves around your chest. It takes a picture of your heart so your care team can see how well your heart is pumping and to make sure the heart's structure is okay.

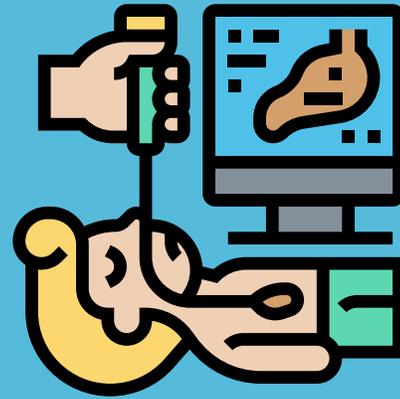
A clear, cool gel will be put on the wand to make it glide better. You may feel some pressure from the wand, but it should not hurt.



Possible Evaluation Appointments



CT Scan: A camera that looks like a big doughnut or tube structure. A CT scan takes pictures of the inside of your body. It may be noisy and make sounds, but it does not hurt.



Endoscopy: This test uses a thin tube with a pinpoint camera at the end to take pictures of your throat and stomach. You will be asleep during this procedure so you should not feel anything.

Now What? The Selection Committee.

After all of those tests and appointments, your transplant team will have a meeting to talk about you. This is called the **selection committee**. They will **decide** if they think you should have an **intestinal transplant** or if they can think of something else to help make you healthy.



The Transplant Waitlist

If your team decides you need a transplant, then your information is placed on a waiting list for the whole country. This means that kids who need intestinal transplants from California are on the same waitlist as kids who need them from Ohio. This list is run by an organization known as the United Network for Organ Sharing or UNOS.



Where do my organs come from?

In some cases, when a person passes away from a serious injury or accident, a family can generously **decide to donate** their **organs** so they can be used to help other people. This is known as **deceased donor donation** and is a very special gift.

Organs that can be donated include the:



Stomach



Lungs



Heart



Liver



Kidneys



Small Intestine



Large Intestine (Colon)



Pancreas

How long will I wait for my transplant?

No one knows how long you will wait for your transplant. Your transplant team is waiting for the perfect set of organs to come for you.



The best thing you can do is always be prepared for your transplant call. You can do this by following your care team's instructions and staying healthy.

How can I prepare for my transplant?

Waiting for your transplant can be long. Here are some things you can do to make sure you are prepared for your transplant and hospital stay:



1. Have a **bag packed** with comfy clothes, your favorite blanket, and your favorite toy or stuffed animal.

2. **Make a photo collage** with pictures of you and your family that you can hang up in your hospital room after your transplant.



3. During your wait, you will have many different emotions. You may feel scared or worried about your transplant or maybe a little excited that you will feel better soon. Be sure to share your feelings with your parents, family, or transplant team. They are there to help.

4. **Stay active** so you are strong for your transplant. 5. **Follow the instructions** from your transplant team.

What happens when I get "the call?"

- You will have to go to the hospital so your transplant team can get you ready for your transplant. First, your team will tell you to stop eating and drinking.
- When you get to the hospital, many people from your transplant team will ask many questions and do many tests.
- **Do not be alarmed.** This is **all normal.** They are just making sure it is safe for you to have your transplant.

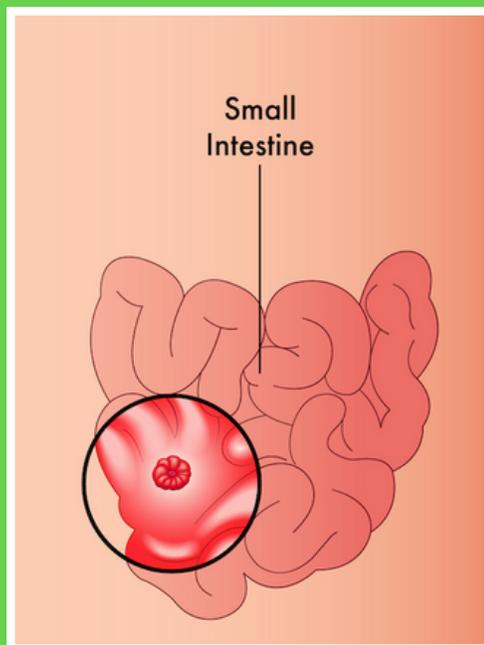
What happens once I am prepped and ready to go for my transplant?

- When it is time to go have your transplant, you will be able to say "see you soon" to your family, and then the transplant team will wheel you into the operating room.
- A special doctor, known as the anesthesiologist, will give you a sleepy medicine called anesthesia. This medicine will help you fall asleep, and you will not hear, feel, or see anything during your transplant.
- Once the transplant is done, you will wake up.

What will it be like when I wake up from my transplant?



Your **tummy will hurt** from where your new organs were placed, but you can tell the nurse if it is hurting. They can give you some medicine to make it feel better.



You may have **many tubes and lines** connected to you. It is important that you **do not pull or tug** on these; they are important in monitoring you and your new organs.

You may have an **ileostomy**. This is an opening in your tummy that looks like a **little red bump**. It connects to your small intestine and lets poop come out of your body into a bag on your belly.

Going Home

Once you are healthy enough to leave the hospital, your transplant team will let you go home. This is very exciting, but it also means you have to remember some very important instructions from your transplant team.



Important Things After Your Transplant



1. **Stay active.** Now that you have received your transplant, you can get back to being a kid. **Keep** your body **moving** to make your muscles strong and help your body grow.

2. **Always follow the instructions** from your transplant team and take your **medicine.**



3. **Eat a well-balanced diet.** Now that you have had a transplant, you should be able to start eating food by mouth. Enjoy sweets and treats sometimes, but remember to eat your fruits and vegetables to get the nutrients you need to grow strong and healthy.

4. **Stay clean and infection-free:** Now that you have had a transplant, you are on medications that make your immune system weaker, which means you can get sick easier.

What is the immune system and anti-rejection medication?

Your immune system is the part of your body that protects you from germs that could make you sick.

After your transplant, you will need to be on special medications known as **anti-rejection medications or immunosuppressants**. These make sure your immune system does not try to hurt your new organs.

However, since anti-rejection medicines make your immune system weaker, there is a **higher chance** that you can become **sick with an infection**.

How can you help prevent infection?

- #1 to infection prevention: **Wash your hands**.
- Stay away from large crowds and groups of people.
- Wear a mask.
- Do not share food or drink with others.
- Do not play with friends or classmates who are sick.
- Clean your room and bathroom regularly.
- Follow food safety tips, including avoiding buffets, raw meat, raw fish, deli salads, and meat.

Find tips for a healthy home from the Nemours [video here](#). and hand-washing [videos from the CDC here](#).

HOW TO WASH YOUR HANDS!

WASH FOR 20 SECONDS BY SINGING HAPPY BIRTHDAY TWICE.



Apply soap to your hands



Rub your hands palm to palm



Rub back to hands



Scrub between your fingers



Clean around each of your thumbs



Rub your fingertips into your palm



Rub your wrists. Repeat for both hands



Rinse your hands with water



Use a disposable towel or tissue to completely dry your hands

Your Feelings After Transplant

- Having a transplant is a huge deal in a person's life, especially as a kid.
- You may be feeling many emotions and these may be very confusing to you.
- Sometimes you may feel happy that you are better, while other times, you may feel sad.
- Share your feelings with your support systems. This may be your parents, family members, your transplant team, a friend, or a counselor.
- And remember, these **feelings are normal**. Many kids across the country feel the same way as you.



The best thing to hold onto
in life is each other.

AUDREY HEPBURN

Do you want to learn more?

Visit us on **Transplant Unwrapped for Kids** where you will find helpful kid-friendly videos and activities.

Remember to always ask your parents or guardian before using the internet or any other unknown source.



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www.transplantunwrapped.org



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