



INTESTINAL TRANSPLANT FOR KIDS

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



Transplant
UNWRAPPED

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)

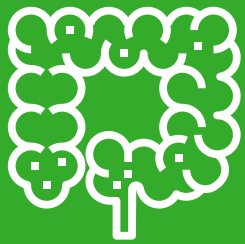


The **stomach** is a stretchy muscular sack that releases digestive juices and acid to help breakdown food. The muscular contractions of the stomach, known as peristalsis, pushes the food out of your stomach and into your small intestine.



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

The **small intestine** breaks down the food more, allowing the nutrients and energy it contains to pass through the lining of the small intestine and give your body the **fuel** it needs.



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



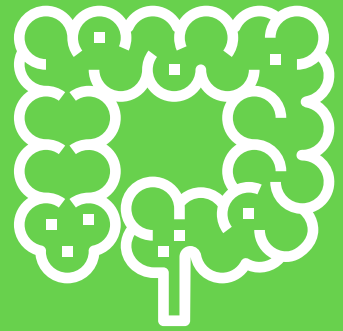
The mush that is left then moves to the last portion of the digestive tract known as the **large intestine**. The large intestine helps to absorb any water or minerals that may have been left-over. The remaining substances is known as feces, or **poop!**



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 just 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 **total parental nutrition (TPN)**.



Why can't I stay on TPN forever?

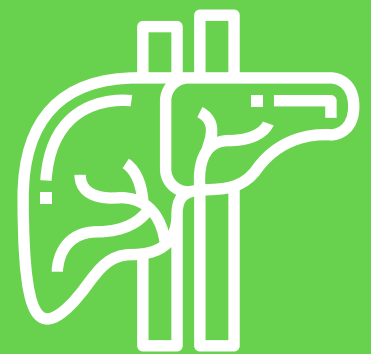
- **TPN** helps your body get the food and nutrients it needs, but it also can **cause problems** and can be difficult for your body to handle.
- TPN can sometimes lead to **serious infections, blood clots**, or it can cause **damage** to your **liver**, which is another important organ in your digestive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

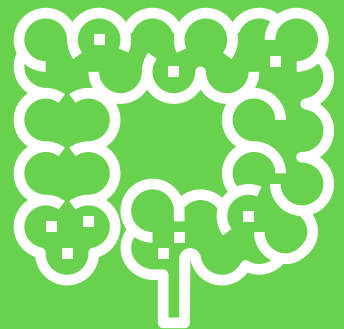
- You must be on TPN and the TPN must be causing you some sort of problem.
- As discussed above, the TPN may be causing serious infections, blood clots, or problems with your liver.



- You also must have a condition that makes it so you are not able to **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** and your doctor may recommend intestinal transplant.



Transplant Evaluation

- If your doctor recommends you for an intestinal transplant, you first must go through **many tests and appointments** to make sure that it is the right choice for you.
- These **may seem scary** and overwhelming at first, but the whole transplant team is there for you and wants to **help** you.

People You May Meet:

- **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.



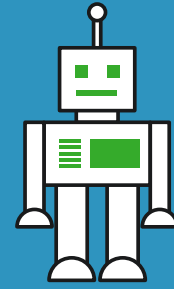
- **Transplant Nurse Coordinator:** This is a nurse that will help you through your entire transplant journey. Do not be afraid to ask them any of your questions.



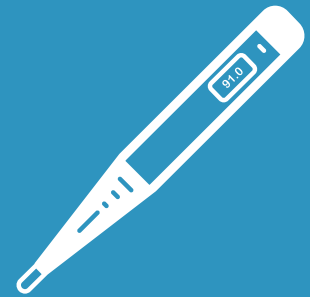
- **Social Worker:** This person makes sure your family is ready to take care of you before and after transplant.



- **Child Life Specialist:** This person makes sure you have a fun and good experience when going through transplant.



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



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



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



Tests You May Have:

- **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 is painless. Watch [this video](#) on getting a blood-draw.
- **EKG:** Sticky pads are placed on your chest, arms, and legs and tells the doctors how well your heart is beating. The test is pain-free.



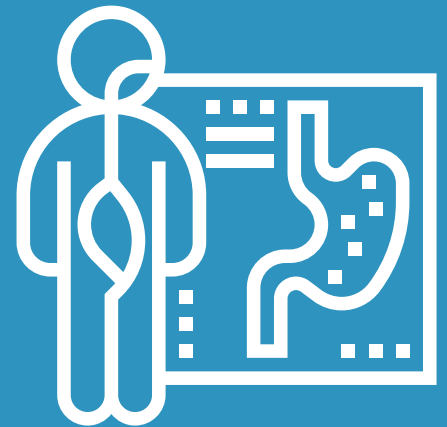
- **Echocardiogram:** This test uses a wand that moves over the skin over your heart to take a picture of your heart to see how it is looking. A clear, cool gel will be put on the wand to make it glide better.



- **CT Scan:** A camera that looks like a big doughnut or tube structure that takes pictures of the inside of your body. It may be noisy and make sounds, but it is pain-free.



- **Endoscopy:** A procedure that uses a thin tube with a pin point 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.



Waiting List

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.



How long will I wait?

- No one knows how long you will wait.
- The doctor is just waiting for the perfect set of organs to come for you.
- The best thing you can do is always be prepared for the call by following your doctor's orders and staying healthy.



Where do my organs come from?

In some cases, when a person dies from a serious injury or accident, the family can **choose to donate** their **organs** so they can be used to help other people.

The doctors will make sure the organs are healthy and will work well in your body.

What happens when I get "the call?"



- You will have to go to the hospital so they can get you ready for the big operation.



- This may be both exciting and scary.



- When you get to the hospital, there will be many doctors and nurses asking a lot of questions and doing many tests.

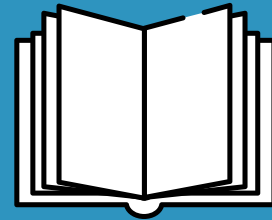
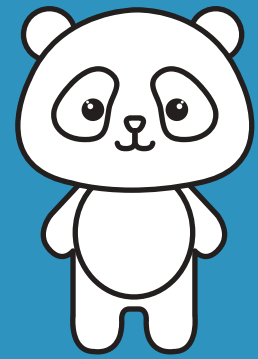


- Do not be alarmed, this is all normal. They are just making sure that you are not sick and it is safe for you to have the surgery.



Make sure when you head to the hospital you don't forget to bring a few of your **favorite things**, such as:

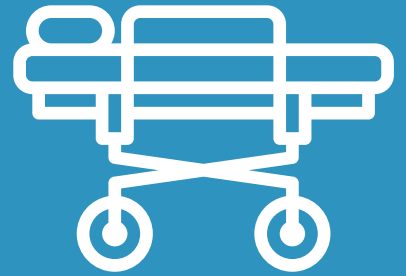
- Book
- Blanket
- Stuffed Animal
- Your Favorite Toy
- iPad or other handheld electronic



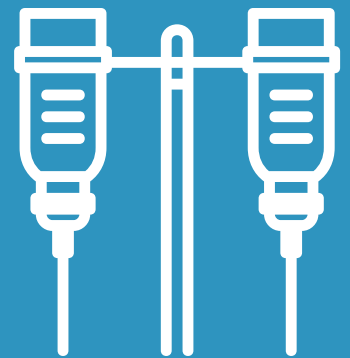
Fun Fact! Your heart beat changes based on the music you are listening too. So, if you are nervous about your upcoming surgery, you should listen to slow, calming music to help slow down your heart beat.

What happens when I am prepped and ready to go?

- 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.



- 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 until you wake up when the surgery is complete.



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

- Your **tummy will hurt** from where the new organ was placed, but you can tell the nurse if it is hurting a lot and they will **give you some medicine** to make it feel better.
- You will have many tubes and lines connected to you.
 - It is important that you **do not pull** or tug on any of these because they are important in monitoring your new organ and helping everything work correctly.

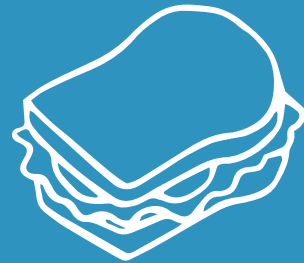


- You may have an **ileostomy**: An opening in your tummy that the end of your small intestine is connected to and lets poop come out of your body.



- It looks like a little red bump sitting on your tummy. It will have a bag attached to collect the poop.

- At first, you will not be able to eat. But soon your new intestine will start to wake up and you will be able to try food.



Fun fact! Poop is made up of mostly water, about 75%! The remaining 25% is a stinky combination of fiber, bacteria, cells, and mucous.

Going Home and Post-Transplant Life

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 rules from your transplant team.

Important Things Post-Transplant

- **Stay active.** Now that you have a new organ you can get back to being a kid.
 - **Go outside** and play with friends, ride a bike, or take a walk in the park.
 - **Keep** your body **moving** to make your muscles strong and help your body grow.



- Always take your **medicine**.
 - You may have to take a lot, but these medicines help to keep the new organ healthy.
 - Some are called 'anti-rejection' medications.
 - Since the new organ in your body is not your own, sometimes your body wants to attack it and damage the new organ.
 - To help stop this from happening your doctor has you take special medicines called immunosuppressant medications or 'anti-rejection' medications.
 - If you stop taking these medicines your body may reject your organ and you could become very sick.



Stay clean and infection free: Now that you have had a transplant you are on medications that make your immune system weaker.

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

Since this part of you does not work as well after transplant, it is **more likely** that you will **become sick**.



How can I prevent infection?

- Number one infection prevention: Wash your hands.
- Stay away from large crowds and groups of people.
- Do not share food or drink with others.
- Don't play with friends or classmates who are sick.
- Clean your room and bathroom on a regular basis.
- Follow food safety tips, including avoiding buffets, raw meat and fish, deli salads and meat.

Find tips for a healthy home [video here.](#)

Find hand-washing [videos here.](#)

Handwashing 101

Proper hygiene keeps you infection free and your new organ thriving.

*Source:
World Health
Organization*

01

Wet your hands before applying soap.



02

Bring your palms together and rub soap all over the palms and backs of your hands, including between the fingers.



03

Wash your hands for at least 20 seconds.



04

Wipe your hands with a clean towel or paper towel and avoid rubbing too vigorously.



Eat well.

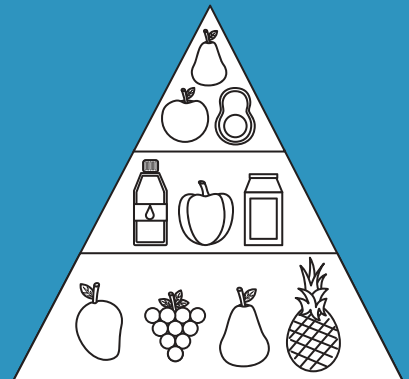
- With your new intestine you finally are able to eat by mouth.



- **Enjoy** the food you are able to eat, but remember that you need to give your body fuel to help it grow into a strong adult.



- Be sure to enjoys sweets sometimes, but also remember you need to eat a **balanced diet** with fruits and vegetables, too.



Talk to your **support systems**.

- Having a transplant is a huge deal in a person's life, especially as a kid.
- You are 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.
- Talk about these feelings with your parents, your transplant team, or a counselor.
- These **feelings are normal**.



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

Do you want to learn more?

Visit us on our **Kids Korner** page where you will find helpful and kid-friendly videos, activities, and websites.

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



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www.transplantunwrapped.org



www.transplantunwrappedkids.org



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References:

1. The human digestive system. (2019, April 17). Retrieved June 14, 2020, from <https://www.natgeokids.com/uk/discover/science/general-science/your-digestive-system/>
2. Digestive System Facts for Kids - Stomach, Intestines, Saliva, Esophagus. (n.d.). Retrieved June 14, 2020, from <https://www.sciencekids.co.nz/sciencefacts/humanbody/digestivesystem.html>
3. Definition: Kidney (for Parents) - Nemours KidsHealth.(n.d.). Retrieved June 15, 2020, from <https://kidshealth.org/en/parents/kidney.html>

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