#### Authors

Stuart S. Kaufman George V. Mazariegos Jorge D. Reyes

# Intestinal Transplantation

Facts about intestinal transplantation.



American Society of Transplantation 15000 Commerce Parkway, Suite C Mount Laurel, NJ 08054 Phone: 856-439-9986 • Fax: 856-439-9982 • E-mail: ast@ahint.com www.a-s-t.org

The information presented and opinions expressed herein are those of the authors and do not necessarily represent the views of the Society.

## **Intestinal Transplantation**

### The Normal Intestinal Tract

The digestive tract breaks food down into small pieces. The body absorbs these pieces to create energy. The digestive tract is a hollow tube and is divided into several parts. Each part has a special purpose. These parts are as follows:

- The esophagus. This is the tube that moves food from the mouth into the stomach.
- The stomach. It mainly stores food before it enters the small intestine.
- The small intestine. This is where most food is broken down and absorbed into the body.
- The large intestine (or colon). It absorbs the water from digested food and forms solid stools.



The small intestine is about 7 to 8 feet long in newborn infants

and grows to about 20 feet by adulthood. The small intestine is made up of three parts:

- The first part is the duodenum, which is about 12 inches long in adults. It is connected to the stomach. Pancreas and liver (bile) fluids drain into the duodenum.
- The middle of the small intestine is the jejunum, which makes up about half of the small intestine.
- The lower small intestine is called the ileum.

## **Intestinal Failure**

The small intestine is the most important part of the digestive system. Most people can live without a stomach or large intestine, but it is harder to live without a small intestine. When all or most of the small intestine has to be removed or stops working, nutrients must be put directly into the blood stream (intravenous or IV) in liquid form. These nutrients are called **"total parenteral nutrition"** or **TPN**. When a person has intestinal failure, they will always need TPN, because the digestive tract will not get better over time.

## **Causes of Intestinal Failure**

There are two types of intestinal failure:

- 1. The small intestine may be too short to digest food correctly. This is called "short bowel syndrome."
- 2. The small intestine or other parts of the digestive tract are not working right.

When the intestine is too short, a person may have a lot of bowel movements. They may not get enough nutrients and lose too many body fluids. This is why they need TPN. Infants can have intestinal failure for different reasons than older children and adults.

Causes of short bowel syndrome in infants are:

- Birth defects that require removal of abnormal intestine.
- Part of the bowel can die for no known reason (Necrotizing enterocolitis). This is rare, but can happen in infants who were born too early.

Things that can damage the intestine and cause short bowel syndrome in older persons are:

- Radiation treatment for cancer that is near the intestine
- Not enough blood flow to the intestine because of hardening of the arteries.

- Crohn's disease, an illness that causes damage to the intestine
- Removal of the intestinal tract because certain stomach tumors had to be removed

## When the Digestive Tract Does Not Work Properly

There are two main reasons the intestine may not work properly:

- The inner lining of the intestine is not working. This inner lining is where the pieces of food are broken down even smaller and taken into the bloodstream.
- o The other type of functional intestinal failure is called pseudo-obstruction. The intestine acts as if there is a blockage, but there is none. It can develop in children or adults. Patients with pseudo-obstruction have problems with bowel movements and experience severe nausea and vomiting, particularly when they try to eat.

# What is intestinal transplantation?

Transplantation is a surgery to put a donated organ from someone who has died into a person who needs it. A part of small intestine can be transplanted into a person. If needed, other organs can be transplanted at the same time.

The first time doctors tried transplanting intestine, it did not work well because the patients' immune systems rejected the new intestine. The body's immune system protects it from disease and foreign substances. The bodies of the transplanted patients treated the new intestine as a foreign substance. Now, there are medications to help prevent the immune system from rejecting the transplant.

## Why would someone need an intestinal transplant?

Giving nutrition to a person through their veins (TPN) can cause serious problems if it needs to be done for a long time. If a person cannot take TPN and cannot digest food, they will starve.

Some problems that can happen with TPN:

- We do not know the reason, but almost half of people treated for a long time with TPN get problems with their liver. In some people, the liver problems can be severe or can even cause them to die.
- TPN has to be given in a very large vein. TPN can damage these large veins and there are only 6 veins large enough to use. If all of these are damaged, there is no way to feed the patient, so when three large veins become damaged, doctors begin to consider an intestinal transplant.
- Putting TPN into the large veins can cause serious infections. If this happens a lot, it may be time for an intestinal transplant.

## Why are some people not able to have an intestinal transplant?

In some patients, the problems caused by the transplantation are not worth the benefit. That happens in these situations:

- The patient may die from the surgery because of other serious illnesses
- Have tumors near the intestine that cannot be completely removed
- Have serious infections at the time of surgery
- Have serious problems with their immune system, including immune deficiency syndrome (AIDS)

Because of problems like these, each patient is checked by a doctor to decide if a transplant would be good for them.

#### How is an intestinal transplant done?

Organs used in the transplantation are called "grafts." Intestinal grafts often come from someone who has died. An intestinal transplant is a difficult procedure. It is a difficult procedure because scar tissue from earlier surgery may make it hard to replace the old, damaged intestine and because a large amount of bleeding can happen during the surgery.

The part of the original intestine that does not work is removed. The surgeon usually attaches one end of the graft to the end of the original intestine. Sometimes, the upper end of the graft is connected directly to the stomach. If a stomach and intestine are transplanted together, the stomach is attached to the esophagus at one end and the end of the intestine is attached either to the large intestine or, if needed, goes to a hole (stoma) leading outside the body (a colostomy). Waste that comes out of the intestine through the hole goes into a bag (a colostomy bag).



A colostomy

# After the Surgery Is Done

In many ways, care after an intestinal transplant is the same as after any big operation.

- You will be given fluids through the veins, good nutrition to help healing, and antibiotics and antiviral drugs to reduce the chance of infection.
- Anti-rejection drugs are given because the immune system naturally tends to attack a transplanted organ as if it were a dangerous virus or bacteria. Organ rejection is most common within the first three to six months after transplant.
- It is important to take the medication exactly as the doctor instructs. This helps make sure the transplant works and makes it less likely that the patient will get an infection or other problems.

#### Anti-rejection drugs:

The medicines that help your body accept the new intestinal transplant are the same drugs used for other transplants. Your doctor may choose your medication from many drugs. Some of these drugs are:

- Tacrolimus. This one is used the most often.
- Corticosteroids.
- Antibodies that block some of the action of the immune system.
- Mycophenolate mofetil (Cellcept®) and sirolimus, also known as rapamycin (Rapamune®).

Because of the new drugs used today to help the body accept a transplant, most patients do well with the transplant.

#### Nutrition after the transplant:

- You might be able to begin eating as soon as a few days to two weeks after surgery
- Until you can eat, liquids are given by mouth, into your vein (IV), or feeding tube. TPN may be needed for a while after surgery, but is decreased as the patient begins to eat.
- The goal is to have you able to eat within four to six weeks after the transplant. Some patients may need fluid given through the vein for several more months.
- Infants who have never eaten solid food before the transplant often will not eat well after transplant and may need tube feeding with a liquid diet. Low-allergy formulas are used at first because anti-rejection drugs may cause food allergies. Solid food may be added later.
- Most food is easy to digest. You may see increased stools (diarrhea) after drinking sweet liquids like juice or after eating fried foods. Eventually, most pediatric patients can eat or drink milk products.

#### Testing for rejection of the transplant:

There is no blood test to determine if rejection of the intestinal transplant is taking place, and there may not be symptoms when rejection is just beginning. An instrument called an endoscope is often used to take samples (biopsies) of the transplanted intestine soon after the operation. This instrument is passed into the intestine through the stoma. Biopsies may be taken weekly or monthly in the beginning, when the risk of rejection is highest, and then maybe once a year after the first year. If the patient also has a liver transplant, blood tests will check for liver damage and to see if a liver biopsy is needed.

If a biopsy does show rejection, treatment is started in the hospital, and may include high doses of a corticosteroid (methylprednisolone) and increased doses of tacrolimus. More tests may be done to see if the condition has improved or if other medications are needed. In a few cases of severe rejection, the graft may have to be removed and another transplant performed, but this is rare.

#### Prevention of infection:

The risk of infection is high after an intestinal transplant. This is because the graft cannot be sterilized (cleaned of all germs) before it is placed into the patient. Also, the intravenous (IV) tubes in the large veins must be left in place for a while and can cause infection. To help decrease the chance of infection, the patient is given antibiotics. The anti-rejection drugs make some common virus infections dangerous to a patient who has gotten a transplant. Most Transplant Centers give antiviral drugs for several weeks or months after transplant. Periodic blood tests are also run after transplant to look for two of the common viruses, cytomegalovirus (CMV) and Epstein-Barr Virus (EBV).

# After the Patient Goes Home

Many of the things that were done in the hospital must also be checked at home to make sure the transplant continues to function well. These things include:

- Checking the patient's vital signs: temperature, heart rate, and blood pressure. A fever or higher heart rate may be an early sign of infection or not enough fluids (dehydration).
- Checking the patient's body weight
- How much fluid the patient is drinking (or getting by IV) and how much solid food the patient is eating.
- Stool output. Diarrhea or having less stool output may be a sign of a serious problem that needs immediate medical attention.

Intestinal transplantation is difficult and problems happen often. Many Transplant Centers require patients to live near their Transplant Center for several months after surgery. After returning home, you can go back to your regular doctor for help with what to eat, blood pressure, and fluids. However, most Transplant Centers prefer to help you with the anti-rejection drugs. The Transplant Center may also make sure tests are done if there are problems with the graft. Most Transplant Centers also want to be told of any major change in condition, hospitalization, or a visit to an Emergency Department.

Frequent blood tests are an important part of post-operative care. Before returning home choose a local lab for testing. In the beginning, blood tests are done once a week or more. After a while, testing is done once every one or two months. Test results are sent to the Transplant Center.

# Medications at Home

To keep the new part of the intestine healthy, you must take several drugs at the correct times. Drugs that are needed are:

- Anti-rejection drugs to prevent rejection of the transplant.
- Drugs to prevent infections that are common in patients taking anti-rejection drugs.
- Extra nutrition (nutritional supplements) and medicines are often needed even if the intestinal transplant is working well.
- Blood thinners to prevent blood clots.
- Drugs for high blood pressure.

Some medications, particularly anti-rejection drugs, are taken forever; others are required for only a short period of time after transplant. Anti-rejection drugs have many side effects. They must be taken exactly as prescribed to be effective. Too little medication allows the immune system to destroy the new intestine. Too much medication interferes with fight-ing infection and causes other side effects. Taking doses at the wrong time can reduce the drug's effectiveness. After awhile, if there are no signs of rejection, the patient may be able to take fewer drugs. However, rejection can still happen even though medications are taken properly; in that case more drug therapy will be needed.

The following can be signs of transplant rejection. If any of these occur, call the doctor:

- Diarrhea or increased fluid coming from the stoma
- Loss of appetite or weight loss
- Swelling and pain in the abdomen
- Nausea and vomiting
- Blood in the fluid coming from the stoma or in the stool
- Change in color or appearance of the stoma
- If you have a fever and no other illness
- Swelling or unusual redness of the stoma

The patient needs tests if any of these things happen.

# **Preventing Infection at Home**

Drugs that prevent rejection decrease the body's ability to fight serious infections. You can protect yourself after leaving the hospital in several ways:

- Check your temperature if you feel warm. If you have a fever, swollen lymph glands, coughing, nighttime sweats, or new snoring, there may be an infection and you should notify your doctor.
- Get the blood tests that the doctor orders.
- Take all the medications exactly the way the instructions say.

- Avoid getting germs:
  - Avoid people who have infections -- especially chicken pox, a cold or flu, mononucleosis (mono), or tuberculosis (TB). Transplant patients who were around someone with an infection should tell their Transplant Center doctor right away.
  - o Take antibiotics before and after dental work or other types of medical treatments, if your doctor recommends it.
  - Wash your hands very well, especially before eating, after touching objects that carry germs (money, doorknobs, and public telephones), and after using the bathroom, especially in public restrooms.
  - o Avoid compost piles, construction sites, damp hay, and rotting plants, fruits, and vegetables.
  - Wear gloves during activities such as gardening.
  - o Wear shoes when outdoors.
  - o Cover your body, including arms and legs, when hiking.
  - Some vaccines use live virus (polio, tuberculosis, measles) and are bad for a person who is on anti-rejection drugs. Do not get these vaccines and avoid people who have recently had any of them.
  - o Get tetanus shots as needed (in case of an animal bite or a dirty cut, for example).
  - o Get a flu shot every year.
  - o Do not share razors, toothbrushes, or eating and drinking utensils.
  - Practice safe sex. Use a condom. Having many sex partners increases the chance of getting an infection, so it is best to only have sex with your long-term partner or your spouse.
  - Drink only treated city or bottled water. If you are not sure the water is clean, as the local water authorities (phone numbers are listed on the monthly water bill) or the EPA Safe Water Hotline at (800) 426-4791.
- If you are around animals and pets:
  - o Avoid contact with animal urine, stool, or vomit, especially bird droppings.
  - o Wash hands well after touching pets.
  - o Do not allow house pets to roam freely outside, especially cats, because they may catch infections outdoors that they can give to humans.

# Getting Back into a Normal Routine

**Sleep.** Transplant recipients sometimes develop the urge to sleep during the day and stay awake at night. Avoid long daytime naps; that will make it easier to sleep at night.

**Regaining Strength.** Transplant recipients are often weak right after transplantation. Exercise rather than rest is usually the best way to regain strength. If possible, exercise under the care of a Physical Therapist. Swimming in a chlorinated pool is usually okay after drainage and feeding tubes have been removed and all wounds and tube sites have healed. Most patients should be able to go back to work or school after an intestinal transplant.

**Driving.** Adult intestinal transplant patients are usually able to drive after surgery, but first check with the Transplant Center. Some medications slow reflexes, and reduce your ability to see or make good driving decisions. If the doctor says it is okay to drive, fasten your seatbelt. The seatbelt will not hurt the intestine transplant.

Alcohol. Most Transplant Centers advise against drinking alcohol after an intestinal transplant.

**Medical Alert Identification.** Many Transplant Centers suggest wearing medical alert identification, such as a pendant or bracelet sold under the brand name MedicAlert® (Tel: 1-800-830-0546 or e-mail: service@medical-id.com). This kind of ID tells others about the transplant if the patient cannot talk. The ID should say what the transplant is, for example, "Intestine Transplant" or "Intestine and Liver Transplant." It should also say that the patient is "On Immunosuppressants" (the anti-rejection drugs) and any other important medical information.