PATIENT'S HANDBOOK ON INTESTINAL TRANSPLANT

Transplant
UNWRAPPED

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HOW TO USE THIS HANDBOOK

This book contains information covering all aspects of intestinal and multivisceral transplant. This ranges from indications and evaluation to post-transplant complications and living. While we try to provide a great deal of information, this is by no means an exhaustive source of information on intestinal and multivisceral transplant that is available. For additional information, please visit our **website** where you can find webinars, pediatric content, additional resources, and a Patient and Caregiver Forum.

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INTRODUCTION

Intestinal and multivisceral transplantation is still a relatively new and uncommon procedure. Dr. Thomas Starzl performed the first successful multivisceral transplant in Pittsburgh, PA, in 1987. The discovery and FDA approval of the tacrolimus protocol for immunosuppression in 1990 transformed the transplant's feasibility. Although advancements made in recent years have led to greater success, the transplant is still only offered to patients with irreversible intestinal failure who have exhausted all other treatment options.

A BRIEF HISTORY OF

INTESTINAL TRANSPLANT

Intestinal Transplants are performed to replace diseased bowels with healthy ones. The procedure has only successfully been completed in the past 30 years.

1905

Scientist **Alex Carrel** conducted first experiments with intestinal transplants in dogs.

1959

Lillehei at the University of Minnesota performed autotransplants and homotransplants in the intestines of dogs.

1960

Starzl performs the first multivisceral transplant on a dog.

1962

Dr. Lillehei **autotransplants** cold preserved bowel.

1968

TPN begins as a treatment for babies born with catastrophic gastrointestinal conditions.

1987

Pittsburgh group transplants a multivisceral graft of the stomach, pancreas, duodenum, small bowel, liver, and colon in a 3-year-old girl using cyclosporine based immuosuppresion.

1989

The first international small bowel transplant symposium convenes in London.

1989

Tacrolimus based immumosuppresion protocol changes intestinal transplant to become a more feasible option.l

1990

Grant reports the first long term survival of a small bowel transplant with enteral autonomy.

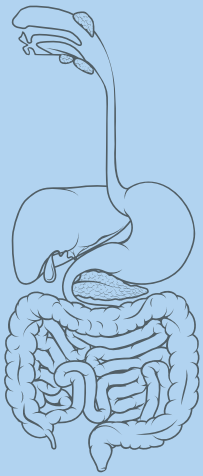
2000

Intestinal transplantation procedures qualify for funding as a service by the United States Health Care Financing Administration (HCFA).

Transplant UNWRAPPED

BASIC ANATOMY AND PHYSIOLOGY OF THE GASTROINTESTINAL SYSTEM

The **gastrointestinal (GI) tract** is a hollow tube from the mouth to the rectum and is divided into many parts:



- **Mouth:** The mouth where mechanical digestion begins. Saliva in the mouth functions to moisten and lubricate food before swallowing and partially digest food particles.

- **Esophagus:** This is the tube that moves food from the mouth into the stomach.

- **Stomach:** In the stomach, glands secrete hydrochloric acid, which helps digest food and destroy bacteria that enter the body with the food. Other than water, little nutrient absorption occurs in the stomach.

Small intestine: Chyme moves from the stomach and into the first portion of the small intestine known as the duodenum. It is in the small intestine where most food is broken down and absorbed into the body.

- **Duodenum:** First part of the small intestine. About 12 inches long in adults. Pancreatic and liver ducts connect to the duodenum to deliver enzymes and other fluids to help digestion.

- **Jejunum**: Middle of the small intestine. Responsible for absorbing carbohydrates, proteins, vitamins, and minerals.

- **Ileum:** Last portion of the small intestine. Absorbs any remaining nutrients left from the jejunum.

Colon: Food moves from the small intestine into the colon. The colon has two main functions: 1) acting as the storage chamber for undigested material and 2) functions to reabsorb water.

Rectum: When initiated, contractions of the rectum and relaxations of the anal sphincter cause defecation and stool deposits.

BASIC ANATOMY AND PHYSIOLOGY OF THE GASTROINTESTINAL SYSTEM

The process of digestion and absorption relies on many components of proper contractions, enzymes, and cell function. If any of these functions are impaired, then the process may not proceed as planned, as seen in patients with intestinal failure.

Fun Fact! Did you know the average person produces 2 pints of saliva every day. That is 32 ounces, or 2 cans of soda.

The Intestinal Transplant Process

What is an intestinal transplant?
Intestinal transplant is when a donated organ from someone who has passed away is placed into a person who requires a new, healthy intestine.

There are SIx Main Steps to Intestinal Transplant:

1.**Indications for Intestinal Transplant:** You first will need to determine if you suffer from a condition that has resulted in intestinal failure. Once this is determined, you must also meet one of the Centers for Medicare and Medicaid (CMS) criteria for intestinal transplant to be considered for an intestinal transplant evaluation.

2. **Intestinal Transplant Evaluation:** The transplant team evaluates you to see if you are a candidate for transplant and determine if you healthy enough to undergo such extensive surgery.

3. **Selection Committee and The Waitlist:** After evaluation, your transplant team presents your case to the selection committee to determine if you should be placed on the national waitlist for an organ transplant.

4. **The Call and Transplant:** After waiting for an unknown period of time, you will receive a call for an organ match.

5. **Post-Transplant Medications:**After your transplant surgery, you will require many medications to make sure your new organ remains healthy.

5. **Post-Transplant Complications:** After your transplant surgery, there is a high likelihood that you may endure some complications. This should not scare you away nor crush your spirits. Complications are normal, and your transplant team will be right by your side to take care of everything as needed.

6.**Post-Transplant Responsibilities:** Once you are stable enough to be discharged from the hospital, you will return home to recover, and you will have to manage your care on a day-to-day basis.

Why might an intestinal or multivisceral transplant be required?

- If your small bowel has **permanently failed**, known as intestinal failure, you may require an intestinal transplant.
- **Intestinal failure** is when the intestine is not able to digest and absorb enough nutrients to support growth and daily function.
- Individuals with intestinal failure require the use **of total parenteral nutrition, or TPN**, which is the delivery of nutrients through the large veins in his or her body.
- Intestinal failure **alone** is **not an indicator** for intestinal transplant; instead, an individual must also have a **complication from total parenteral nutrition** (TPN) or meets Centers for Medicare and Medicaid criteria.

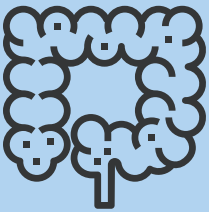
Did you know it was only in 1968 that TPN became a treatment option for babies with intestinal failure.

INTESTINAL FAILURE

As stated above, to **qualify for intestinal transplant** you must:
1) Have an underlying condition or situation that results in intestinal failure and,

2) Develop a TPN related complication or qualify under a CMS criteria, as outlined below.

What is intestinal failure?



Intestinal failure (IF) develops when your small intestine does not provide the necessary long-term nutrition needed to sustain normal life, resulting in the need for TPN.

There are many etiologies (causes) of intestinal failure.

What are causes of intestinal failure?

1. **Mucosal Disorders** (common in the pediatric population)
    a. Microvillus inclusion
    b. Secretory diarrhea
    c. Autoimmune enteritis
2. **Motility Disorders:**
    a. Hirschsprung's disease (see pediatric)
    b. Hollow visceral myopathy and/or neuropathy
    c. Chronic Intestinal Pseudo-Obstruction (CIPO)
3. **Surgical or Anatomical Disorder:**
    a. Volvulus
    b. Gastroschisis (see pediatric)
    c. Necrotizing enteritis (see pediatric)
    d. Ischemia
    e. Crohn's disease
    f. Intestinal atresia (see pediatric)
    g. Other causes of short bowel
4. **Gastrointestinal Neoplasm**
    a. Mesenteric desmoid tumor, commonly associated with Gardner's syndrome
    b. Diffuse polyposis
    c. Carcinoid tumors

INTESTINAL FAILURE: MOTILITY DISORDERS

Chronic Intestinal Pseudo-Obstruction (CIPO) in Adults

- Chronic intestinal pseudo-obstruction (CIPO) is a rare condition that can affect **all segments** of the gastrointestinal (GI) tract.
- CIPO is characterized by **failure of the movement** of intestinal contents through the digestive tract due to the inability to generate suitable motor patterns, either due from a deficit in the neuropathic (nerve) or myopathic (muscle) forces.
- It can be either **primary disease** in which it may be a degenerative or inflammatory process or **secondary** to a neuromuscular disease such as scleroderma, systemic sclerosis, bronchial carcinoma, or amyloidosis.
- Rarely, pseudo-obstruction arises **acutely** in a condition known as **Ogilvie's syndrome.**
  - Ogilvie's is **concurrent with non-gastrointestinal** disorders such as myocardial infarction, infection, or non-operative trauma.
  - This syndrome is **characterized** by acute colonic dilation, pain, and abdominal distention.

A correct diagnosis is three-forths the remedy.

MAHATMA GANDHI

INTESTINAL FAILURE: MOTILITY DISORDERS

Chronic Intestinal Pseudo Obstruction (CIPO)

SIGNS & SYMPTOMS

- Abdominal pain
- Distention
- Nausea and/or vomiting
- Constipation
- Early satiety (fullness)

DIAGNOSIS

- **Manometry:** Measures the contractions of the intestinal tract and can help to localize the functioning areas of the gastrointestinal tract. Manometry can help evaluate functional areas before any surgical intervention.
- **Gastric emptying studies:** Direct, noninvasive measurements of liquid or solid gastric emptying to assess the function of the stomach.
- **Full thickness biopsy:** Full thickness biopsies are useful in the diagnosis of autoimmune or mitochondrial etiology for CIPO. These can get a better understanding of abnormalities of the enteric nervous system.

TREATMENT

- **Nutritional Support:** The majority of patients will require nutritional support, often requiring total parenteral nutrition (TPN).
- **Prokinetics:** Examples include erythromycin, octreotide, or tegaserod.
- **Antibiotics:** These may be used to treat small intestinal bacterial overgrowth.
- **Surgical:** A decompressing gastrostomy or jejunostomy.
- **Small Bowel Transplant:** May be indicated in patients who have TPN dependency and have TPN failure. Important to evaluate the presence or absence of gastric or colonic dysfunction, so the decision can be made whether to proceed with isolated or multivisceral transplant.

Volvulus

A volvulus occurs when part of the intestine is twisted or rotates on itself and the mesentery. The mesentery is the supportive tissue that anchors the intestine to the abdomen's back wall and contains the essential blood vessels, lymphatics, and nerves to supply the intestine. When the intestine twists, it creates a bowel obstruction that cuts off the intestine's blood supply, affecting bowel function and ultimately resulting in death to the bowel if not treated promptly. Extensive bowel necrosis (death) results in the requirement of a massive bowel resection (removal), possibly leaving an individual with short bowel syndrome and the inability to maintain adequate nutrition by mouth. The cause of the twisting is unknown.

SYMPTOMS

Severe abdominal pain
Nausea and vomiting
Constipation
Bloody stools
Abdominal distention.

DIAGNOSIS

Based on a combination of factors including:
Clinical picture
Physical exam
Abdominal x-ray
CT scan
Upper/lower GI barium series.

TREATMENT

Surgical intervention is required. If massive resection is needed, an intestinal transplant to correct short bowel syndrome may be recommended.

INTESTINAL FAILURE: SURGICAL AND ANATOMICAL DISORDERS

Ischemia

The Background:

- **Ischemia** is a general term that means an inadequate blood supply to an organ or part of the body.
- The intestine is supplied by various blood vessels and is a highly vascularized organ.
- The artery called the **superior mesenteric artery** supplies the majority of the small intestine as well as the first portion of the colon up to the splenic flexure, the bend between the transverse colon and descending colon.
- When a blood clot in the superior mesenteric artery (SMA) creates a blockage, it stops the delivery of oxygen to the intestine and results in the **death of the organ.**

SYMPTOMS

Severe abdominal pain
Nausea and vomiting
Abdominal distention.

DIAGNOSIS

Based on a combination of factors including:
Clinical picture
Physical exam
Angiography
CT scan
.

TREATMENT

When a blockage occurs, the necrotic (dead) intestine must be removed, leaving the individual with a short bowel, which is insufficient to provide the essential nutrients required to sustain life. The patient must then be placed on parenteral nutrition (PN) and may qualify the patient for an intestinal transplant evaluation.

INTESTINAL FAILURE: SURGICAL AND ANATOMICAL DISORDERS

Crohn's Disease

Crohn's disease is a type of inflammatory bowel disease (IBD) in which your immune system recognizes the lining of your intestine as foreign. This causes the immune system to attack the intestinal epithelium, causing inflammation. Crohn's disease usually follows a pattern of repeating cycles of intermittent flares in which the condition worsens, and symptoms are present, and then a period of remission in which inflammation is controlled, and symptoms are absent. The symptoms can range from mild to severe and can be disabling.

SIGNS & SYMPTOMS

- Abdominal pain
- Diarrhea
- Fatigue
- Unintentional weight loss
- Anal pain
- **Arthritis**- typically in the larger joints and is most active when bowel symptoms are active.
- **Mouth sores**- usually found between the gums and lower lip, or along the sides of the tongue.
- **Eye inflammation (uveitis or scleritis)-** can cause eye pain, blurry vision, and sensitivity to light.

DIAGNOSIS

Crohn's disease is confirmed through an intestinal biopsy. The specimen is studied microscopically for specific histological features, namely clusters of inflammatory cells called granulomas.

TREATMENT

1. **Anti-inflammatory medications** (e.g. corticosteroids, 5-aminosalicylates, sulfasalazine), can help to counteract and prevent inflammation.
2. **Immunomodulators** (e.g. azathioprine, methotrexate, and 6-mercaptopurine), as well as biologic response modifiers, (infliximab, adalimumab, certolizumab), can reduce the immune response to attack the intestines.
3. For complications such as fistulas, strictures, or obstructions, **surgery** may be recommended.
4. **Surgery** may result in massive resection and short bowel syndrome. In this case, an **intestinal transplant evaluation** may be warranted.

INTESTINAL FAILURE: GASTROINTESTINAL NEOPLASMS

Desmoid Tumors

- Abdominal desmoid tumors account for the majority of intraabdominal (inside the abdominal cavity) tumors leading to an intestinal transplant.
- Although desmoid tumors are benign (not harmful) tumors, they are infiltrative (grow into healthy tissue) and locally invasive in nature, entrap the mesenteric vasculature, and can lead to obstructions and fistulas.
- Desmoid tumors are generally unresponsive to normal chemotherapeutic agents, thus complete surgical removal of the intestine is often required. This leaves the patient with a short bowel that is insufficient to support your nutritional needs.

Gardner's Syndrome

- Desmoid tumors are commonly associated with Gardner's syndrome. Gardner's syndrome is a form of familial adenomatous polyposis (FAP).
- It is not uncommon for Gardner's patients to undergo a total proctocolectomy (removal of colon, rectum, and anus) to treat the primary disease and prevent progression to cancer.
- Apart from a total protocolectomy, resections for desmoid tumors in the intestine can be performed, but multiple resections can lead to short bowel syndrome and insufficient absorption.
- The extensive resection they require will often place the patient in the position to be a candidate for intestinal and/or multivisceral transplant evaluation.

INTESTINAL FAILURE: INTESTINAL REHABILITATION

Before pursuing a transplant, intestinal rehabilitation is usually attempted in patients with intestinal failure. Intestinal rehabilitation is the process of restoring nutritional autonomy in patients with intestinal failure. This means weaning from TPN and onto oral feedings to the point in which one can live life without the support TPN and free from TPN complications.

There are **multiple components to intestinal rehabilitation** and all therapies focus on **maximizing the absorptive capacity of the bowel.**

THERAPIES

1. **Diet Modification:** First Line Therapy
2. **Oral Rehydration Therapy**
3. **Vitamin and Mineral Supplements**
4. **Pharmacological Therapy**
    a. **Anti-Diarrheal agents:** These help slow transit time and increase absorption.
    b. **Proton-pump inhibitors:** These help decrease stomach acid secretion.
    c. **Probiotics or antibiotics:** These help treat small bowel bacterial overgrowth.
    d. **Exogenous bile salts:** These help with fat and calcium absorption
    e. **Teduglutide (GLP2)** also known as Gattex: Used to increase nutrient absorption in short bowel syndrome patients
5. **Surgical Interventions:** These include autologous reconstruction and bowel lengthening techniques such as the Bianchi and Serial Transverse Enteroplasty Procedure (STEP).

If intestinal rehabilitation does not have a favorable outcome and you remain in intestinal failure, you **may be considered for intestinal transplant**; however, intestinal failure alone does not automatically qualify a you for intestinal transplant.

To **qualify**, you must also **meet one of the CMS criteria** (listed on the following page) below prior to an intestinal transplant evaluation.

Centers for Medicare and Medicaid

INDICATIONS FOR TRANSPLANT

- **FAILURE OF PARENTERAL NUTRITION (PN)**
  - PARENTERAL NUTRITION ASSOCIATED LIVER DISEASE
  - CENTRAL VENOUS LINE SEPSIS (>2 TIMES PER YEAR OR FUNGAL)
  - CENTRAL VENOUS THROMBOSIS (>2 TIMES)
  - FREQUENT DEHYDRATION DESPITE IV FLUIDS
- **HIGH RISK OF DEATH**
  - DESMOID TUMORS ASSOCIATED WITH FAMILIAL POLYPOSIS
  - CONGENITAL MUCOSAL DISORDERS
  - ULTRA SHORT BOWEL SYNDROME
- **IF WITH HIGH MORTALITY OR LOW ACCEPTANCE OF PN**
  - INTESTINAL FAILURE WITH HIGH MORBIDITY
  - INTESTINAL FAILURE WITH INABILITY TO FUNCTION
  - PATIENT UNWILLINGNESS TO ACCEPT LONG TERM TPN

Contraindications to Intestinal Transplant

The absolute contraindications are:

- Cardiopulmonary deficiency
- Aggressive malignancy
- Advanced autoimmune disease
- Acquired immunodeficiency syndrome (AIDS)
- Existence of life-threatening intra-abdominal infections or sepsis
- Inadequate social or financial support

Please note: As with most things in this handbook, the contraindications are at the discretion of each individual transplant center and individualized per patient.

Helpful Resources for Step One

The Oley Foundation
Purpose: Striving to enrich the lives of those living with home intravenous nutrition and tube feeding through education, advocacy, and networking.

Short Bowel Syndrome Foundation
Purpose: Education and advocacy for individuals with short bowel syndrome.

International Foundation for Gastrointestinal Disorders
Purpose: Education and research for gastrointestinal disorders. Has specific information on motility disorders, gastroparesis, kids GI disorders, and more.

Gastroparesis Patient Association for Cures and Treatments (G-PACT)
Purpose: Dedicated to increasing awareness of Gastroparesis (GP), Chronic Intestinal Pseudo-obstruction (CIP), and Colonic Inertia (CI).

TYPES OF TRANSPLANT

FOUR TYPES OF INTESTINAL TRANSPLANT

Isolated Intestinal Transplant

- Reserved for patients with irreversible gut failure limited to the small intestine.
- Consists of transplanting only the small intestine.

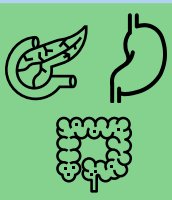
Liver-Intestine

- Indicated for patients with irreversible failure of both the intestine and the liver.
- This is rarely performed now. Usually if a liver is required, surgeons perform a full multivisceral transplant

Multivisceral Transplant

- Indicated for patients with irreversible liver and intestinal failure with extensive GI disease.
- Transplanted organs include the stomach, duodenum, pancreas, small intestine, and liver.
- The kidney will sometimes be included if the patient is in renal failure.

Modified Multivisceral Transplant



- Indicated for patients with irreversible intestinal failure and disease of the GI tract in the absence of liver failure.
- Transplanted organs include the stomach, duodenum, pancreas, and small intestine.

Are you interested in more anatomically correct images for the types of transplant? Take a look at this article:
Imaging of Intestinal and Multivisceral Transplantation.

Step 1.5: Choosing a Transplant Center

When choosing a transplant team and center, there are a number of parameters to consider, including:

- Center specializations and expertise.
- Location, distance from home, and relocation costs.
- Individual center requirements for patient proximity to transplant center while on the waitlist and after transplant surgery.
- Caregiver options and center requirements for caregiver support.
- Insurance coverage and network restraints.
- Transplant survival rates and graft outcomes.
- The number of transplants the center performs each year.

Meeting the team in person and considering team chemistry and trust is also essential to consider. You will want to trust the selected transplant team explicitly when undergoing the rigorous process of evaluation, waitlisting, transplantation, and post-transplant care. Frequently a patient is cared for regarding any issues that may occur related to their transplant by their intestinal transplant team and will receive care from their team in some capacity for the rest of their lives.

Helpful Websites for this Step

Organ Procurement and Transplantation Network (OPTN)
Purpose: Transplant information database contains all national data on the candidate waiting list, organ donation and matching, and transplantation.

The Scientific Registry of Transplant Recipients (SRTR)
Purpose: Important transplant and donation data.

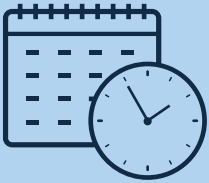
SRTR Transplant Centers Search
Purpose: Search for all transplant centers in the United States.

STEP 2: EVALUATION

The evaluation for transplant consists of many outpatient appointments including:

- Consultations
- Lab tests
- Imaging studies

These tests and meetings help to determine if a transplant is the right treatment, if there are alternative treatments that may help, and if you are well-enough to have a transplant. Each individual transplant center will have their own system for scheduling the evaluation tests and appointments.



Many centers will try to schedule the entire evaluation in a one- to two-week period in order to accomplish everything in a short period of time, especially if you are coming in from out-of-town. It is important to discuss the arrangement with your individual transplant center.

INFORMED CONSENT

Informed consent begins at the start of the transplant evaluation process and continues through transplant. Informed consent ensures that you fully understand the entire transplant process, both pre- and post-transplant. It also provides you with complete knowledge of the possible risks and benefits associated with transplant and gives you the right to make educated health decisions.

Questions to Ask Your Transplant Team to Help Make an Informed Decision:

- What are my choices other than transplant?
- What are the risks and benefits of transplant?
- What does the evaluation process include?
- How long do most patients with my blood and organ type wait at this hospital for this type of transplant?
- How long has this hospital and these surgeons been doing this type of transplant?
- How many of these types of transplants does this hospital or surgeons perform each year?
- Am I allowed to be listed at more than one transplant center (e.g. multi-listing)?
- What are the organ and patient survival rates for my type of transplant at this hospital?
- How do the organ and patient survival rates compare with other centers around the country?
- How does the medical team decide whether or not to accept an organ for me?
- How long will I have to stay in the hospital and the area after my transplant?
- What is the extent of appointments and tests that I will have to endure after my transplant?
- What are the costs should I expect associated with transplant and what financial assistance is offered?

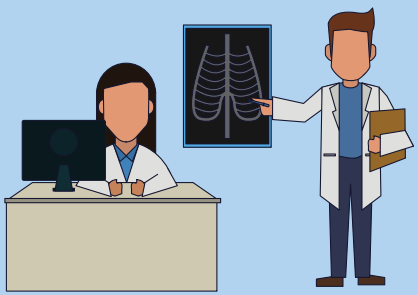
TYPICAL APPOINTMENTS, TESTS, AND CONSULTS

Anesthesiologist	• Determine how to provide safe administration of general anesthesia during transplant
Social Worker	• Assesses support system, compliance history, and motivation for intestinal transplant • Provide support resources
Financial Counselor	• Discuss transplant coverage, costs associated with transplant, and medication costs
Psychiatrist	• Conduct in-depth psychiatric evaluation and assessment
Pharmacist	• Review medications to determine if there are any contraindications to transplant • Address any concerns related to current and potential post-transplant medications

Dentist	• Assess oral health
Gynecologist (females)	• Assess reproductive health
Infectious Disease	• Assess past and current infections • Determine need of vaccinations • Provide education on preventing infections • Provide guidance on travel safety precautions
Transplant Nurse Coordinator	• Provide education regarding the transplant evaluation process and care pre/post-transplant • Allows time to ask any questions you may have and become fully informed
Intestinal Transplant Physicians/ Gastroenterologist	• Assist in medical evaluation and treatment of underlying intestinal disease • Assess ability to respond to medical and dietary intervention
Intestinal Transplant Dieticians	• Assess ability to respond to dietary intervention • Manage nutrition pre/post-transplant • Educate on nutrition therapy and transition to a full oral diet
Intestinal Transplant Surgeon	• Discuss appropriateness of transplant based on evaluation • Educate you about the types of transplant, benefits, risks, and possible complications

The evaluation can be exhausting, but is also your opportunity to ask all of your questions you have for the transplant team and transplant center. Remember, no question is a stupid question!

Because it will be a lot of information, be sure to **write everything down**.



TYPICAL APPOINTMENTS, TESTS, AND CONSULTS

Blood Tests	• Determine how serious organ disease is and which organs are diseased • Determine blood type • Determine immunity or presence of certain viruses
Chest X-Ray	• Assess the lungs
Urine Test	• Screen for urinary tract disease • Test for alcohol and drugs
EKG	• Assess the electrical activity of your heart
Echocardiogram	• Assess the structure of your heart

Endoscopy	• May include colonoscopy, esophagogastroduodenoscopy (EGD), endoscopic retrograde cholangiopancreatography (ERCP), bronchoscopy, small bowel capsule endoscopy • Assesses the inside of organs • Possible source of biopsies
Venous Mapping	• Assess vascular access in the body
Pap Smear (females)	• Screen for cervical cancer

Stress Test	• Assess the cardiovascular capacity of your heart
Cardiac Catheterization	• Diagnose and treat problems with your heart
CT Scan and/or MRI	• Assess how diseased your organ is • Check for any tumors • Check the blood supply to and from the diseased organ
Biopsy	• Help to determine cause of disease • Assess how diseased the organ is
Ultrasound	• Determine size and shape of organ • Check for tumors
Pulmonary Function Test	• Assess function of the lungs
Mammogram	• Screen for breast cancer
DEXA Scan	• Assess bone health

Patient Adherence

Good medical adherence and good communication with your transplant team is an important part of the transplant's success, and for this reason, most transplant centers ask you to review your treatment plan and agree to follow and adhere to an outline of your responsibilities pre- and post-transplant.

Failure to comply with your regiment can result in your removal from the list and/or can result in organ failure post-transplant due to a lack of adherence with appropriate medical regimens and medication protocols. The plan is in place to ensure the best possible outcome for your transplant.

SELECTION COMMITTEE

Once your transplant evaluation is complete your pre-transplant coordinator will present your case in front of the Intestinal Selection Committee to determine the best possible recommendations for ongoing care and intestinal transplant surgery.

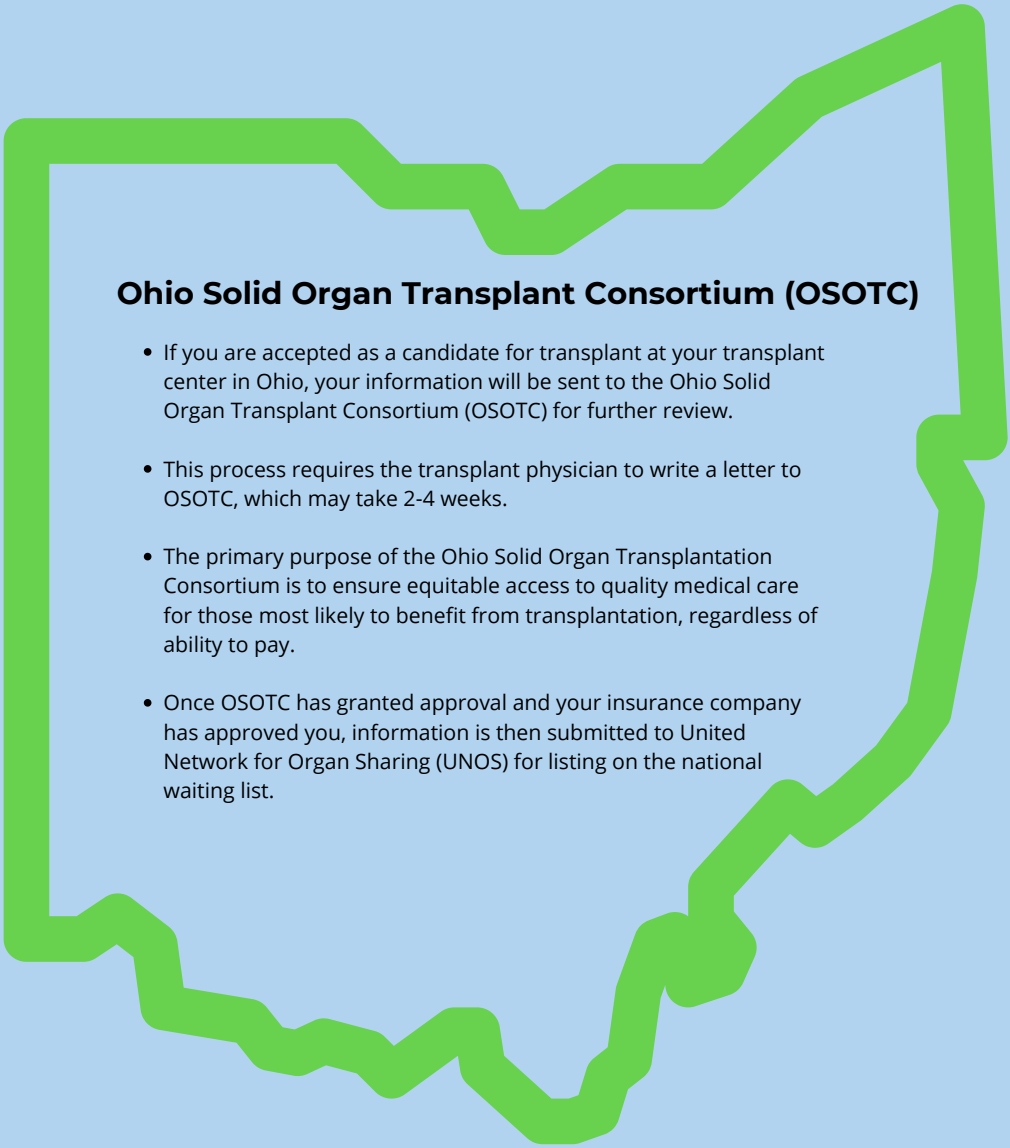
The committee consists of:

- Transplant surgeons
- Gastroenterologists
- Nutritionists
- Social workers
- Ethicists
- Psychiatrists and Psychologists
- Transplant Nurse Coordinators
- Financial Coordinators

The committee will recommend the best options for your care and your coordinator will then relay this information to you.

Note: At this point, for most transplant centers and states you would then be officially listed with UNOS, the national organ waiting list. If you are pursuing an intestinal or multivisceral transplant in any state other than Ohio please proceed to the section on "Waiting List" to continue reading; however, if you are pursuing a transplant in the state of Ohio then read the portion of information below.

SELECTION: OHIO ONLY



Ohio Solid Organ Transplant Consortium (OSOTC)

- If you are accepted as a candidate for transplant at your transplant center in Ohio, your information will be sent to the Ohio Solid Organ Transplant Consortium (OSOTC) for further review.
- This process requires the transplant physician to write a letter to OSOTC, which may take 2-4 weeks.
- The primary purpose of the Ohio Solid Organ Transplantation Consortium is to ensure equitable access to quality medical care for those most likely to benefit from transplantation, regardless of ability to pay.
- Once OSOTC has granted approval and your insurance company has approved you, information is then submitted to United Network for Organ Sharing (UNOS) for listing on the national waiting list.

Now you can move onto the next step of listing and waitlist procedures like the rest of the states.

THE WAITING LIST: WAITING STATUS

The waiting list is a computer database managed by the United Network for Organ Sharing (UNOS). The list contains medical information on every person who is waiting for every type of organ transplant in the US and Puerto Rico.

There are **3 status designations** on the intestinal transplant waiting list as of UNOS most recent policies in 2020:

1.**Status 1:** To assign an intestine candidate status 1, the candidate's transplant program must submit a Status 1 Justification Form to the OPTN. A candidate may be assigned status 1 if the candidate has any of the following conditions:

- Liver function test abnormalities.
- No vascular access through the subclavian jugular, or femoral veins for intravenous feeding.
- Medical indications that warrant intestinal organ transplantation on an urgent basis.

2. **Status 2:** Any **active** candidate that does not meet the criteria for Status 1 must be registered as Status 2.

3. **Inactive Status** (also known as Status 7): If the candidate is temporarily unsuitable for transplant, then the candidate's transplant program may classify the candidate as inactive and the candidate will not receive any intestine offers.

- ***Please note:*** Policy 7.2 waiting time as of July 1, 2020, inactive candidates will accrue waiting time while inactive for ***up to*** a maximum of 30 cumulative days.

If you are **listed for a liver** in addition to an intestine, listing status and waitlist time will vary and policies are based on MELD (adult) and PELD (<12 years) scores. To learn more, read the OPTN policy **document here**.

THE WAITING LIST

Waitlist Removal

In some cases, a patient that was once a transplant candidate is no longer a candidate for transplant. There are two main reasons why an individual ***may be removed*** from the transplant list:

1. Candidate's Health Improves: The transplant candidate's health and function improves and no longer qualifies for transplant. In the event that the candidate's health declines in the future, he or she may be re-listed for transplant.

2**. Candidate's Health Declines**: The transplant candidate's health and function declines to the point that it is no longer safe to perform the transplant surgery. If the candidate's health improves in the future, he or she may be placed back on the list.

Can I reduce Waiting Time for an Intestinal Transplant?

It is limited. An intestinal transplant has two statuses based on medical urgency: Status One and Status Two. Past this listing, organs are given to the person who is the closest match to the donor to have the best chance of success. Neither the transplant surgeons nor your transplant coordinator has any influence over this. If you are listed for a multivisceral transplant or a liver-intestine transplant, your liver listing may set a different priority level for you; however, this is different from the intestinal listing.

THE WAITING LIST

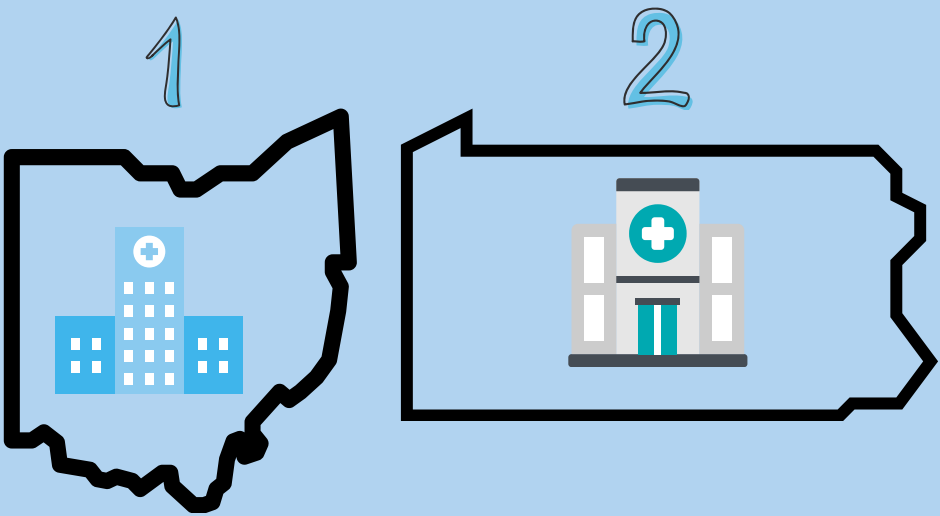
Transferring Waiting Time

- Patients may choose to list at a different transplant hospital and transfer their waiting time to that hospital.
- For information about transferring waiting time, contact the transplant hospital directly.
- The transplant teams at the original hospital and the new hospital are responsible for exchanging information and notifying UNOS of the transfer of waiting time.
- Patients should ask each hospital if they accept transferred waiting time.

THE WAITING LIST

MULTIPLE LISTINGS

- As a patient you have the right to be listed at more than one transplant center.
- Each transplant center has its own policies on multiple listing.
- You will be required to undergo the entire evaluation at each transplant center and become approved by each individual center for transplant.
- Multiple listing is only an advantage if you select transplant centers in different organ procurement organization (OPO) service areas.
- The advantages of having a listing in different geographic locations include access to multiple donor pools, different rules in other regions, and possible shorter average wait times in different areas.



THE WAITING LIST

Coping While Waiting

The waiting time can be **very frustrating.** The unknown of how long it will take is emotionally draining. There are many ways you can help yourself cope during this challenging time:

1.**Try and live your life as normally as possible:** While waiting, still make plans and do things with your friends and family. You may have to put the disclaimer on plans that things may change at any moment' and you may have to cancel at the last minute, but if you keep living your life like it was before being on the list, it will make the wait more manageable and less taxing.

2. **Use your support systems:** Your family, friends, and transplant team are there to support you. Talk to the people around you and express your frustrations and fears. It is not health to keep everything bottled-up. Talking about what is bothering you can help ease the stresses you may be having.

3. **Learn and research**: Part of the frustration with waiting comes from the fear of the unknown, not only from not knowing how long you will wait, but also from not knowing what to expect from the transplant. Learn about the transplant, talk to post-transplant recipients, if possible. Having an understanding will hopefully empower you and make you feel more comfortable in your current situation.

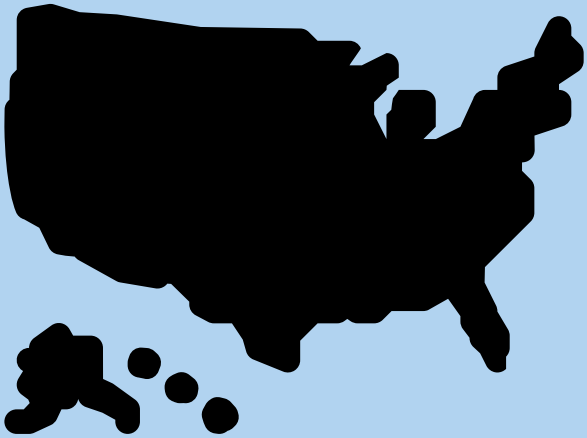
4. **Get help:** If necessary, speak with a counselor, social worker, or psychiatrist if you feel anxious or down about the waiting period. It is not unusual to become depressed in these situations, and a medical professional may find a treatment modality that could be of great benefit.

ORGAN ALLOCATION AND MATCHING

The United Network for Organ Sharing (UNOS) is the organization that coordinates the nation's organ transplant system. Under contract from the federal government, UNOS operates the Organ Procurement and Transplantation Network (OPTN), which serves to maximize the use of deceased organs and collect and analyze data about the patient waiting list, transplants, and organ matching.

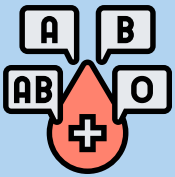
Previously, for liver and intestinal organ allocation, UNOS had divided the US into 11 geographic regions to help facilitate transplantation. Within each region, there were a total of 58 organ procurement organizations (OPOs) that served to increase the number of registered donors and coordinate the donation process.

In February 2020, the organ allocation policies changed to distribute organs based on ***acuity circles***. This bases organ distribution on nautical miles (NM) rather than geographical boundaries. You can read more about the implementation and policies **here.**

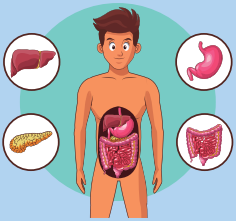


What factors affect the allocation and matching of organs?

Blood type: Exact match of blood type is required for intestinal transplant.



Body size: The organs must fit properly into your body cavity.



Time spent waiting for a transplant: Your waiting time starts from the date that the program lists you.

Medical urgency: For intestine, you will be listed as Status 1 or 2. If listed for a liver, MELD or PELD also contribute.

Distance between transplant hospital and donor hospital, based on nautical miles (NM) and acuity circles:

Classification	Candidates registered at a transplant hospital that is at or within this distance from the donor hospital. **NM** = Nautical Miles	Who are:
1	500NM	Status 1 and a blood type identical to the donor.
2	500NM	Status 1 and a blood type compatible with the donor.
3	Nation	Status 1 and a blood type identical to the donor.
4	Nation	Status 1 and a blood type compatible with the donor.
5	500NM	Status 2 and a blood type identical to the donor.
6	500NM	Status 2 and a blood type compatible with the donor.
7	Nation	Status 2 and a blood type identical to the donor.
8	Nation	Status 2 and a blood type compatible with the donor.

THE MATCHING PROCESS

An organ is donated.

Data about the organ is entered by the local OPO into the computer system, including organ size and condition, blood type, and tissue type.

A list of compatible candidates is generated.

Candidates are ranked based on allocation policy for the organ and how closely the candidates characteristics match the donors.

An organ is offered to the transplant team which decides whether to accept or reject the organ based on what is best for the patient.

An organ is accepted or rejected. The process continues until the organ is placed.

THE CALL

GETTING THE CALL

- Be sure to answer your phone at all times of the day and night.
- When a donor organ becomes available, a transplant coordinator will contact you, discuss the offer, and you will make a decision together on whether to accept or reject the organs.
- Some of the success of your transplant depends on organ donor risk factors which include the age, medical, and social history of the donor and the condition of the organ when it arrives in the operating room, which your surgeon will discuss with you.
- If you accept the organ(s), you most likely will have to go to your transplant center immediately.
- You usually will be asked to immediately stop eating and drinking and will be instructed on which medications to stop or continue.

The organs you will receive will be **deceased donor organs.** Deceased donor organs are donated organs from a person who has suffered irreversible brain damage and has been declared dead by a doctor and can be divided into **two types:**

1. **Standard Criteria Donor (SCD):** Organs from deceased donors who were young and healthy and did not have major health problems. Cause of death is usually an accident or sudden illness. The organs are expected to function well after they are transplanted.

2. **Expanded Criteria Donor (ECD):** A deceased donor that is not considered “standard.” This type of donor may be considered for you based on your disease and how sick you are. At the time of the offer, the surgeon will review this with you and help you make a decision on whether to accept or reject the offer.

THE CALL

BE PREPARED FOR THE CALL

1.Have a **bag packed** that you can take with you when you get the call for organs. Also, make a list of other things you may want to 'grab' on the way out the door (such as a cellphone, cell phone charger, headphones, etc.) that you may not pack in the bag ahead of time.

2. If you have **pets and/or children**, have a **plan** in place of how they will be taken care of when you get the call.

3. If you live alone, make sure you have a plan for someone to take care of your mail/ newspaper/ plants, etc.

4. Be sure to have a reliable **source of transportation** for when you get the call.

"Dry Run"

Sometimes the transplanted organ is unable to be used and you may be sent home. This is known as a ***dry run.*** This can be very disappointing, but you should have an understanding before transplant that this is very common. The transplant surgeons are looking out for your best interest and will only give you the most suitable organs.

THE SURGERY

If the the transplant does proceed, you can expect the surgery to last anywhere from 8-16 hours. This is individualized and will depend on many factors, including which organs are being transplanted. While you are in surgery, your family will receive periodic updates from the operating room (OR) on how you are doing. Exact procedures will vary by transplant center.

THE HOSPITAL STAY

After the transplant surgery, you will go into the Surgical Intensive Care Unit (SICU) for a few nights, or maybe longer, depending on how you are doing. Once you are stable, you will be moved to your transplant center's designated transplant floor. Everyone is different, and the duration of stay after transplant can vary greatly. On average, patients stay about 4 weeks post-transplant surgery, but this is very individualized. Your transplant team will determine when you are stable enough to be discharged.

Things to Expect Right After Intestinal Transplant

ENDOTRACHEAL TUBE

- A tube called an endotracheal tube will be in your throat when you wake up to help you breath.
- You will not be able to talk while this tube is in.
- The tube will be removed once you are stable and able to breath on your own.

NASOGASTRIC TUBE

- Also known as an NG tube, will be coming out of your nose and is used to drain the stomach contents until the transplanted bowel is fully functional.
- Generally removed 1-2 weeks post-transplant.
- Helps with nausea and vomiting.

JACKSON-PRATT DRAINS (JP)

- Placed in the abdominal cavity to drain fluid.
- Generally you will have 2-4 drains.
- Removed once output significantly decreases.

ILEOSTOMY

- Surgically-created opening in the last segment of bowel (the ileum) through which waste passes.
- Essential for monitoring for rejection via biopsies.
- Not all transplant centers place ileostomies, it's on a case-by-case basis

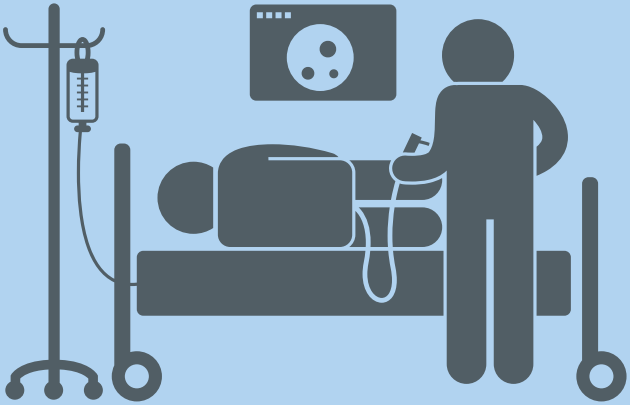
OUTPUT MONITORING

- Output from all sources (ileostomy, drains, urinary catheter) and intake (IV fluids, liquids from medications, tube feedings, oral hydration) will be measured and recorded.

DAILY MONITORING

- Dressings will be changed daily.
- Special monitoring equipment that will check your heart rate and blood pressure every 15 minutes.
- Bloodwork will be drawn every morning.
- Weight will be checked daily to ensure adequate nutrition and hydration levels.

INTESTINAL ENDOSCOPY (ILEOSCOPY) AND BIOPSY



- The only way to monitor for rejection of the transplanted intestine is via a biopsy of the transplanted bowel.

- During the procedure, an endoscope is inserted into the stoma and advanced 4-8 inches.
  - The physician visually can observe the transplanted bowel.

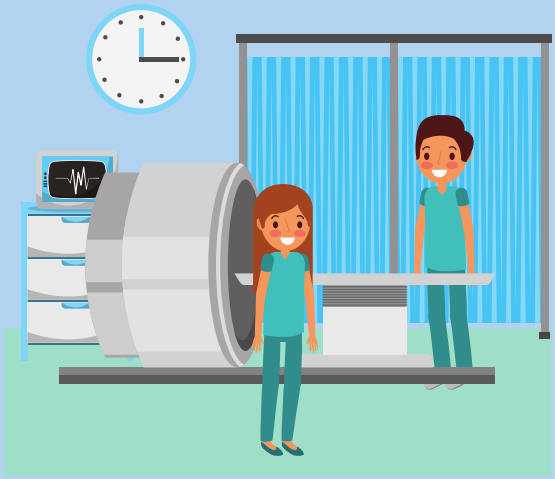
  - A small pen-point biopsy (a piece of tissue) is taken from the transplanted bowel and analyzed under a microscope to determine if changes indicate rejection.

  - The first biopsy usually takes place 5-10 days after the transplant surgery, but this may vary per transplant center. Some centers choose only to conduct biopsies if the patient is symptomatic with signs of rejection.

  - It is common to repeat surveillance biopsies 1-2 times a week while you are in the hospital after transplant. Your transplant team will decrease the frequency based on how you are doing. Once again, this frequency varies per center, and some centers will not do any surveillance biopsies. Check with your center for the plan for you.

POST-TRANSPLANT COMPLICATIONS

Complications are common after an intestinal or multivisceral transplant. The positive thing is that your transplant team will be vigilant in monitoring you for all complications and will be on top of treating you if any do arise. The following pages contain a sampling of the potential complications that may occur. This is not an all-inclusive list. If you are concerned that you are experiencing a complication after your transplant, or you are concerned about the possibility of complications, it is always best to contact your transplant team directly.



COMPLICATIONS

ACUTE CELLULAR REJECTION (ACR)

General Information

This occurs when your body detects the new intestine as foreign and, as a result, attacks the organ. Most patients will experience some form of rejection in the first 3-6 months post-transplant. This type of rejection can be classified as indeterminate, mild, moderate, or severe based on the histologic findings on your endoscopic biopsy.

Signs and Symptoms

- Fever
- Abdominal pain
- Abdominal distention or swelling
- Nausea/ vomiting
- Increase in stoma output
- Changes in the appearance of stool
- Blood in stoma output
- Change in appearance or color of stoma
- Loss of appetite/ weight loss
- Often causes no physical symptoms

Diagnosis

- Diagnosis based on pathological findings of a biopsy taken during the scope of your new intestine.
- The scope may be just surveillance and routine since acute rejection will not show signs or symptoms frequently.
- Other times, signs or symptoms may prompt your transplant team to order a scope and biopsy if they suspect you are in rejection.

Treatment

Treatment ultimately depends on the severity of the rejection.

- Mild rejection may just require adjustment of your immunosuppression medications and high doses of corticosteroids.
- Moderate to severe rejection may require heavier immunosuppression agents such as Thymoglobulin or Campath.
- Your transplant team will determine the best course of treatment for you based upon your immune status and biopsy results.

COMPLICATIONS

Antibody-Mediated Rejection

For intestinal transplants, unlike other solid organ transplants, antibody-mediated rejection is poorly defined, and the frequency and clinical significance remains uncertain. For what is known, antibody-mediated rejection usually develops within the first two weeks after intestinal transplant in the presence of circulating immunoglobulins (IgG). Monitoring of donor-specific-antibody (DSA) levels, along with biopsies and clinical correlation, can help with the diagnosis of antibody-mediated rejection.

Chronic Rejection

General Information

This type of rejection develops **months to years** after the transplant has been completed and after acute rejection episodes have subsided. It appears to be a combination of both antibody and cell-mediated rejection. Overall, there is fibrosis and scarring of the transplanted organs.

Signs and Symptoms

- Abdominal pain and/or distention.
- Increased output from ostomy.
- Poor oral intake and/or decreased appetite .

Diagnosis

- The only way to definitively diagnose chronic rejection is through a full thickness biopsy of the graft to look at the histology.

Risks for chronic rejection include:

- Acute rejection within the first month of transplant.
- Isolated small bowel graft (in many reports it has been shown that including the liver in the graft has an immunoprotective effect in preventing rejection).
- Greater number of acute rejection episodes.
- Older recipient age.

COMPLICATIONS

General Infection

General Information

Since you are on high doses of immunosuppression post-transplant, you are at an increased risk for infection. Many small bowel transplant patients will have a bacterial infection within the first two months post-transplant. Because of this, it is crucial to monitor for infections. Your transplant team will likely ask you to take your temperature daily after your transplant and be aware of your constitutional symptoms (e.g., fatigue, muscle aches).

Signs and Symptoms

- Oral temperature > 100.4oF (38 degrees C)
- Chills or sweats
- Cough
- Shortness of breath
- Sore throat
- Earache
- Sores or rashes in mouth or skin
- Burning with urination
- Cloudy or foul-smelling urine
- Pain, redness, warmth on incision site
- Wound or cut that won't heal
- Increased or watery diarrhea with a foul smell
- Redness, swelling, drainage around drainage tubes

Diagnosis

- Bloodwork
- Urinalysis
- Blood cultures
- Stool cultures
- CT scans of chest or abdomen

Treatment

Treatment is going to be based on the type of infection that you have and whether or not you are able to tolerate oral medications. You will be given either oral or IV antivirals, antibacterials, or anti-fungals depending on the organism you are infected with.

COMPLICATIONS

Cytomegalovirus (CMV)

General Information

CMV is a widespread virus. Once infected, your body retains the virus for life. Most of the time, people do not realize they have the virus because it does not cause problems in healthy people; however, after transplant, you are immunosuppressed, and the virus may reactivate. When CMV reactivates, it may cause signs and symptoms and be a serious infection for transplant patients.

Signs and Symptoms

- Fever
- Chills
- Sweats
- Muscle aches
- Pneumonia
- Inflammation of the small intestine (CMV enteritis)
- CMV retinitis (infection with CMV in the eye)
- Liver inflammation

Diagnosis

- CMV surveillance is conducted via a blood test that uses CMV PCR. This is able to detect whether or not CMV can be found in the blood.
- If CMV is suspected to be in other organs, then further testing may be warranted.
- An ophthalmologist may be consulted in order to test for CMV retinitis and/or a biopsy may be taken of the intestine if CMV enteritis is suspected.

Treatment

If CMV does reactivate and cause infection, usually a patient will be treated with IV ganciclovir. In the event that the CMV is resistant to ganciclovir, then foscarnet or cidofovir are utilized; however, these medications can be toxic to the kidneys, so they must be used with caution. Your transplant team will determine the best treatment.

Prophylaxis for CMV

Usually intestinal transplant patients will be given oral valganciclovir for the first 3-6 months post-transplant as prophylaxis, meaning to prevent, CMV from reactivating in the months right after transplant.

COMPLICATIONS

Urinary Tract Infection (UTI)

General Information

UTIs are common with immunosuppressed patients. These infections can involve the urethra, the bladder, and/or the kidneys. A variety of different organisms can cause these infections

Signs and Symptoms

- Burning or pain with urination
- Feeling the urge to urinate more frequently and urgently
- Foul smelling urine
- Blood in urine
- Pain in the lower back (if the kidney is infected)
- Fever

Diagnosis

- Urinalysis
- Urine cultures

Prevention

- Avoid bubble baths
- Wear cotton underwear
- Drink plenty of water
- After toileting, always wipe front to back
- Pee often and avoid 'holding it'

COMPLICATIONS

Shingles

General Information

- Caused by a reactivation of the same virus that causes chickenpox (Varicella).
- When the virus is reactivated, it will cause an outbreak of shingles (rash, blisters). You can get chickenpox when exposed to the drainage from these lesions.

Signs and Symptoms

- One to three days before the rash appears symptoms may include: pain, tingling, and burning on the side of the chest, neck, forehead, back, hip, or leg
- Rash and sores appear in clusters of blisters usually in a strip on one side of the body, torso, or face
- You will no longer be contagious when all lesions are scabbed over.

Diagnosis

- Shingles is usually diagnosed based on the history of pain on one side of your body, along with the telltale rash and blisters.
- Your transplant team may also take a tissue scraping or culture of the blisters for examination in the laboratory.

Treatment

- Contact your transplant team immediately.
- You will need to have a V-ZIG injection (varicella-zoster immunoglobulin) within 3 days of exposure (note- the injection may not prevent shingles, but it will lessen the severity of it).
- If you do get shingles even after the V-ZIG injection, your transplant team may require you to be admitted and started on acyclovir until the lesions are crusted over and the team feels you are safe to be discharged.

COMPLICATIONS

Aspergillosis

General Information

Aspergillus is a common fungus (mold) that lives in decaying vegetable matter, soil, and dusty areas. For healthy people, it is of little concern, however, for those that are immunosuppressed it can cause a serious fungal infection.

Signs and Symptoms

- Fever and chills
- Bloody cough
- Shortness of breath
- Chest pain
- Joint pain
- Nosebleed
- Skin lesions

Diagnosis

- Chest CT or Chest X-ray
- Sputum test
- Tissue and blood tests

Treatment

If you contract the infection then your team may treat you with antifungal medications such as voriconazole or amphotericin B.

This is a very common fungus that can be found on decaying leaves, compost, plants, trees, and grain crops. If you are doing yardwork outside, it is always best to wear a mask to avoid inhaling the fungal spores.

COMPLICATIONS

Pneumocystis Jiroveci Pneumonia (aka pneumocystis carinii or PCP)

General Information

This is a serious infection that causes inflammation and fluid buildup in your lungs. It is caused by a fungus called Pneumocystis jiroveci that spreads through the air and is very common. For normal, healthy people, this fungus is not harmful, but for transplant patients with a weakened immune system, it can cause a very serious infection.

Signs and Symptoms

- Fever
- Dry cough or wheezing
- Shortness of breath
- Fatigue
- Chest pain while breathing

Diagnosis

- Fluid from lungs
- Biopsy from lungs
- Blood tests

Treatment

Patients are usually given prophylaxis (preventative treatment) with Bactrim (Sulfamethoxazole / Trimethoprim) three times per week. In the event that you cannot tolerate the oral medication, then a monthly breathing treatment of Pentamidine may be suggested.

COMPLICATIONS

Epstein Barr Virus (EBV) and Post-Transplant Lymphoproliferative Disorder (PTLD)

General Information

Epstein Barr Virus is a common virus that infects a majority of the adult population. In healthy adults, it usually results in the common manifestation known as 'mono,' and the individual's immune system can typically fight off the infection. However, in immunocompromised transplant patients, specific immune cells are suppressed and cannot keep the proliferating B cells in check. The Epstein Barr Virus that had been 'asleep' in the patient's immune cells called B cells 'wakes up' and begins to replicate. This viral replication goes uncontrolled by the transplant patient's immune system and leads to PTLD.

Signs and Symptoms

- Malaise, feeling of unease/ illness
- Fatigue
- Night Sweats
- Fever
- Weight Loss
- Swollen lymph nodes

An overall feeling of not being well.

Diagnosis

Diagnosis of PTLD is based on looking at the entire clinical picture and considering many different tests. Your transplant team will conduct a thorough physical and exam, especially taking note of any lymph node enlargement. They most likely will get extensive blood work, possible imaging studies (CT scan, PET scan, and/or MRI), urinalysis, and/or lumbar puncture.

Treatment

The first line of treatment for PTLD is lowering immunosuppression. If this does not solve the problem, your team might consider starting you on a medication called Rituximab, which has been shown to have very positive results in treating PTLD. More refractory cases may be treated with chemotherapeutic agents or localized radiation. As always, your transplant team will choose the treatment best suited to your particular case.

COMPLICATIONS

Graft vs. Host Disease (GVHD)

General Information

GVHD occurs in all types of transplant, however, it is of major concern to intestinal transplant due to the large amount of immune tissue that the intestine contains. GVHD results when the donor's cells (the graft) view the patient's healthy cells (the host) as foreign and begin to attack and damage them.

Signs and Symptoms

- **Skin reactions:** Itching; red rash on the upper trunk, neck and feet; blisters on the palm, soles, and abdominal skin.
- Mouth or tongue lesions
- **GI manifestations:** Diarrhea, nausea, vomiting.
- **Hepatitis or liver inflammation:** May lead to jaundice or yellowing of the skin.

Symptoms can vary based on if the disease is local on the skin or effecting a particular organ.

Diagnosis

Usually a tissue biopsy of the affected skin will be used to diagnose GVHD along with clinical picture and patient history. Blood tests will often be taken to help manage the condition and to check liver function. If gastrointestinal symptoms are present, an endoscopy may be ordered.

Treatment

In self-limited, mild skin cases of GVHD no treatment may be necessary. In disseminated disease, steroid therapy is the treatment of choice along with adjustments in immunosuppression.

COMPLICATIONS

Blood Clots

General Information

A blood clot is a clump of blood that has changed from a liquid to a gel-like or semi-solid state. Clotting is a necessary process that your body undertakes in certain circumstances to prevent yourself from losing too much blood. Sometimes, your body forms clots in your veins when they are not needed and these can be dangerous. If the clot in your vein accidentally breaks free from your vein and travels to your lungs or heart, it can get stuck and prevent blood flow, prompting a medical emergency.

Blood clots are common after surgery, especially after a big operation like an intestinal transplant. Clots can form anywhere in your body, including your arms, legs, and/or abdominal vessels. It is essential to move as much as possible after transplant to avoid getting any blood clots. Still, if you notice any of the following symptoms, you must immediately contact your transplant team.

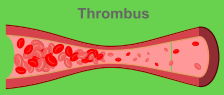
Signs and Symptoms

- Cramping/ pain
- Swelling, usually of one area
- Reddish or bluish skin discoloration
- Area warm to touch

Diagnosis

- Clinical picture
- Doppler ultrasound
- Venography
- MRI
- Angiogram
- Blood tests

Treatment



Treatment of blood clots is a very tricky balance. Your transplant team will most likely start you on some form of anti-coagulation 'blood thinning' medication to treat your blood clots. Usually, you first will start with heparin, an IV anti-coagulation medication, and then often will switch to warfarin (Coumadin) the pill form of the anti-coagulation.

LONG-TERM COMPLICATIONS

Avascular Necrosis (AVN)

General Information

Avascular Necrosis or AVN is a condition that results from a lack of blood flow to the bones of the joints resulting in bone death. The most common reason for AVN is chronic steroid use. Generally, transplant patients are on high doses of steroids during transplant and in the immediate post-operative period and remain on some level of steroids for the remainder of their lives. Because of this, many intestinal and multivisceral transplant patients will develop some extent of AVN in one or more joints.

The most common joints for AVN include hips, knees, and ankles; however, it can occur in any joint of the body, including the jaw, wrists, hands, elbows, and shoulders.

Signs and Symptoms

- It is a very painful condition, causing a deep, throbbing, aching bone pain that is usually made worse by activity.

Diagnosis

- **X-ray:** Detects advanced disease.
- **MRI:** Detects early disease and gold standard of diagnosis.
- Other testing modalities can include a CT scan or a bone scan (in nuclear medicine via a radionuclide injection, not a DEXA or bone density scan like you get for osteoporosis which is a very different condition from AVN).

Treatment

- **Early stages:** Symptom relief. If your status allows, your physician may recommend taking NSAIDs, but generally, transplant patients are advised against taking anti-inflammatory medications due to the bleeding risk.
  - Topical anti-inflammatory agents, such as Diclofenac, may be prescribed to help alleviate some of the pain in the joints.
  - Other modalities, such as ice, may help to relieve swelling.
  - The use of assistive devices like crutches or walkers may help to alleviate the stress placed on the joints and reduce pain.
- **Advanced disease** and when joints have collapsed: Joint replacement or fusion may be recommended.

Every treatment is individualized and will be recommended by your transplant team or by your referred orthopedic doctor.

LONG-TERM COMPLICATIONS

Osteoporosis

General Information

Osteoporosis is a condition that results when the osteoclasts, or the bone cells that breakdown your bone, are working at too fast of a rate compared to the osteoblasts, or the bone cells that are creating new bone. The osteoclasts breakdown too much bone and create a 'porous' bone structure, resulting in weak bones. This occurs mainly in weight-bearing areas of your bone, such as your lower back and spine, hip, or wrist. Sometimes your bone can become so weak and brittle that a small fall or injury can cause your bone to break or fracture.

Signs and Symptoms

- Usually, you do not notice osteoporosis until a fracture or break occurs, in which at that time you may experience pain or swelling in the area.

Diagnosis

- **DEXA, or Dual-Energy X-Ray Absorptiometry S**can, or a bone density scan: This test uses enhanced x-ray technology to measure the amount of bone loss.
- You are assigned a z-score for each area of bone and this determines whether your bones are healthy, whether you have osteopenia, or whether you have osteoporosis.

Treatment

Depending on the extent of your bone loss will determine what the best treatment is for you. If you are at the beginning stages, your physician may recommend just supplementing with calcium and vitamin D. If your bone loss is more significant, it may be suggested that you get an infusion of Reclast or Prolia. Each plan is individualized, and your transplant team may refer you to an endocrinologist so they can determine the best course of treatment for you and if there is an underlying cause that is hastening the progression of your osteoporosis.

LONG-TERM COMPLICATIONS

Renal (Kidney) Dysfunction

General Information

Patients are most likely to be on high doses of immunosuppression medications after an intestinal transplant, particularly tacrolimus, which is in a class of drugs known as calcineurin inhibitors. This particular medication class is particularly hard on the kidneys and can lead to kidney dysfunction and disease. Many post-intestinal transplant patients will develop kidney disease, often leading to the need for dialysis and, ultimately, a kidney transplant.

Diagnosis and Monitoring

Your transplant team will take blood on a consistent basis to monitor the function of your kidneys. Your serum creatine, BUN, and glomerular filtration rate (GFR) are indicators of kidney dysfunction:

- **Serum creatinine:** This is a waste product that comes from muscle activity. When kidneys are working well, they remove creatinine from the blood.
- **Glomerular filtration rate (GFR):** A math formula using the person's age, race, gender, and serum creatinine is used to calculate a GFR. This number is used to figure out the stage of chronic kidney disease (CKD).
- **Blood Urea Nitrogen (BUN):** A normal waste product in your blood that comes from the breakdown of protein from the foods you eat and from your body metabolism. It rises with decreased kidney function as well as when you are dehydrated.

Staging and Treatment

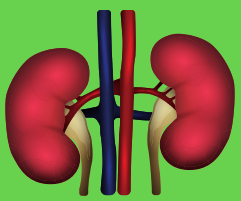
Stage 1 with normal or high GFR (GFR > 90 mL/min)

Stage 2 Mild CKD (GFR = 60-89 mL/min)

Stage 3A Moderate CKD (GFR = 45-59 mL/min)
Stage 3B Moderate CKD (GFR = 30-44 mL/min)

Stage 4 Severe CKD (GFR = 15-29 mL/min)

Stage 5 End Stage CKD (GFR <15 mL/min)



If you are in stage 4 or stage 5, it is likely that you will need dialysis and/or a kidney transplant.

COMPLICATIONS

Cancer

General Information: Skin Cancer

Malignancy rates are higher in all transplant recipients. The risk of cancers such as Kaposi sarcoma, non-Hodgkin lymphoma, nonmelanomatous skin cancers, and cancers related to viral infections, is significantly increased.

Nonmelanomatous squamous cell and basal cell skin cancers are the most common malignancies in transplant recipients. Because of this, yearly skin checks with a dermatologist is recommended for all intestinal transplant recipients.

Reduce your risk of skin cancer by:

- Using sunscreen whenever you go outside.
- Cover up when you go outside, including arms, legs, and neck.
- Use lip balm, lips can get sunburned!
- Get a skin check yearly by a dermatologist and do routine skin checks on yourself weekly.
- Avoid direct sunlight at all times.
- Wear hats when in the sun.

Risk factors for developing skin cancer include:

- History of skin cancer prior to transplant.
- Presence of premalignant skin lesions (warts or keratosis).
- History of exposure to UV rays.
- Older age.
- Male gender.
- Fair skin phenotype.
- Immunosuppression: duration and type.

General Information: Other Cancers

Other cancers, such as prostate, cervical, breast, and colon, transplant patients are also at an increased risk. All transplant patients should receive appropriate screenings for each of these cancers or as their transplant team sees fit based on their history and individual needs, existing co-morbidities, overall life expectancy, and preference for screening.

Most transplant centers require ***annual mammography and pap smear for female intestinal transplant patients*** and a ***yearly prostate exam for male patients.***

Talk to your transplant team about appropriate screenings and your family's cancer history for appropriate recommendations.

MAINTENANCE MEDICATIONS POST-TRANSPLANT: DEFINITIONS

What are immunosuppressants?

- When you receive an organ transplant, your body senses the new organ as foreign, and your body's immune system attacks it.
- Immunosuppressive medication helps reduce the risk of your body rejecting the new organ by lowering your immune response.
- Since you have a decreased immune response, this also means that you are more susceptible to all types of infections.
- You will have to take these medications for the rest of your life, and it is vital for the survival and longevity of your transplant.
- Examples: Prograf (tacrolimus), CellCept, Sirolimus, Prednisone

What are prophylactic medications?

- A prophylactic is a medication or a treatment designed and used to prevent a disease from occurring.
- You will take various medications after transplant to help prevent opportunistic infections you are now more susceptible to because of the immunosuppression medication you have to take.
- Examples:
  - Sulfamethoxazole/ Trimethoprim (Bactrim)
  - Acyclovir (antiviral)
  - Nystatin (antifungal)
  - Clotrimazole (antifungal)
  - Pentamidine (alternative to Bactrim)
  - Valganciclovir (antiviral)

MAINTENANCE IMMUNOSUPPRESSIVE MEDICATIONS POST-TRANSPLANT

Tacrolimus (Prograf)- Main Immunosuppression Medication

Tacrolimus (aka Prograf or FK506) is an anti-rejection or immunosuppressive medication that most of intestinal transplant patients take post-transplant that functions to prevent rejection of the graft by suppressing the immune system. It usually comes in the form of a capsule that you swallow and its absorption can be affected by changes in your diet and other medications that you take, so you must follow any instructions that your transplant team or pharmacist gives you regarding to taking this medication.

Common Side Effects

- Increased risk of infection
- High potassium
- Low magnesium
- High cholesterol
- High blood pressure
- Kidney problems
- High glucose level (diabetes)
- Abnormal dreams
- Tremors/ tingling
- Hair thinning/ loss
- Headaches

Important Tips and Special Instructions:

- Take around the same time each day to keep a constant level in the bloodstream
- Do not eat raw shellfish or oysters.
- Avoid grapefruit or grapefruit juice (e.g. Sunny Delight, Ruby Red juice).
- Do not have immunizations without doctor's approval.
- Always have enough supply of medicine on hand- skipping this medicine means that you could be putting yourself at risk of going into rejection and losing your graft.
- Avoid infection: your immune system is not as strong as it once was because of this medication, be sure to be aware of this and wash your hands and stay away from ill individuals.
- Follow the dosage schedule carefully.
- Missed dose: If missed, take as soon as possible; if close to the next dose, do not take a double dose.

MAINTENANCE IMMUNOSUPPRESSIVE MEDICATIONS POST-TRANSPLANT

Prednisone

Prednisone is known as a corticosteroid and is an immunosuppressive medication. It works to prevent organ rejection by suppressing the immune system. Prednisone comes in tablet form. Dosing will be unique to each patient.

Common Side Effects

- High blood pressure
- Increase in appetite and weight gain
- Steroid induced diabetes
- Vision changes
- Skin changes (acne, thinning of skin, stretch marks)
- Increased sensitivity to the sun
- Thrush
- Swelling of hands, ankles, face
- Osteonecrosis

Important Tips and Special Instructions:

- Have enough medicine on hand: skipping this medicine means that you could be putting yourself at risk of going into rejection and losing your graft.
- Do not have immunizations without checking with doctor.
- Avoid infection: Your immune system is not as strong as it once was because of this medication, be sure to be aware of this, wash your hands, and stay away from ill individuals.
- Follow the dosage schedule carefully.
- Missed dose: If missed, take as soon as possible; if close to the next dose, do not take a double dose.

MAINTENANCE IMMUNOSUPPRESSIVE MEDICATIONS POST-TRANSPLANT

Mycophenolate Mofetil (CellCept)

Mycophenolate Mofetil is an anti-rejection or immunosuppressive medication that intestinal transplant patients may take post-transplant that functions to prevent rejection of the graft by suppressing the immune system. It comes as a capsule, tablet, or liquid suspension. Take with water on an empty stomach or with food. Do not crush or break before swallowing.

Common Side Effects

- Loss of appetite
- Stomach pain
- Nausea, vomiting
- Diarrhea
- Weakness
- Shakiness
- Muscle or leg pain
- Dizziness, drowsiness, headache
- Tremors, sweating, flushing
- Decreased white blood cell or platelet counts

Important Tips and Special Instructions:

- Do not store in direct heat or light.
- Do not store medicine in a bathroom or near the kitchen sink as moisture can cause it to breakdown.
- Always have enough supply on hand: skipping this medicine means that you could be putting yourself at risk of going into rejection and losing your graft.
- Inform provider if you are taking antacids with aluminum or magnesium or acyclovir, they interfere with CellCept.
- Get doctor's approval for vaccinations.

MAINTENANCE IMMUNOSUPPRESSIVE MEDICATIONS POST-TRANSPLANT

Sirolimus (Rapamune)

Sirolimus is an anti-rejection or immunosuppressive medication that intestinal transplant patients may take post-transplant that functions to prevent rejection of the graft by suppressing the immune system. It comes as a tablet or oral solution.

Common Side Effects

- Acne
- High cholesterol, high triglycerides
- Constipation
- Rash
- Low potassium
- Headache
- Loss of energy
- Muscle or joint pain
- Mouth ulcers
- Slow wound healing

Important Tips and Special Instructions:

- Take around the same time each day to keep a constant level in the bloodstream.
- Do not eat raw shellfish or oysters.
- Avoid grapefruit or grapefruit juice.
- Do not have immunizations without doctor's approval.
- Avoid infection: Your immune system is not as strong as it once was because of this medication, be sure to be aware of this, wash your hands, and stay away from ill individuals.
- Always have enough supply of medicine on hand: Skipping this medicine means that you could be putting yourself at risk of going into rejection and losing your graft.
- Store at room temperature, away from moisture, direct sunlight, and excess heat.
- Missed dose: If missed, take as soon as possible; if close to the next dose, do not take a double dose.

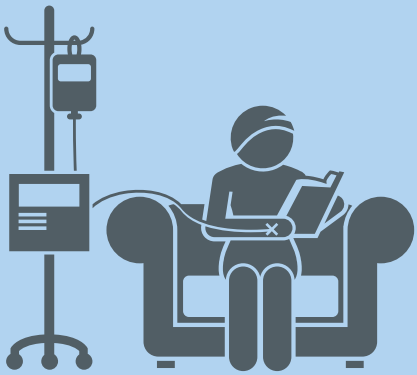
MAINTENANCE IMMUNOSUPPRESSIVE MEDICATIONS POST-TRANSPLANT

Thymoglobulin

Thymoglobulin is an anti-human thymocyte immunoglobulin that is derived from rabbits and functions to suppress a particular type of immune cell in the body called T cells. If you are in acute rejection, your transplant team may choose to use thymoglobulin as an addition to your maintenance immunosuppression to help save your graft. Thymoglobulin is given intravenously.

Common Side Effects

- High blood pressure (hypertension)
- Joint or muscle pain
- Abdominal pain
- Increased levels of potassium in the blood
- Low counts of platelets and white blood cells
- Headache
- Fever and/or chills
- Shortness of breath



Your first time in acute cellular rejection (ACR) may seem frightening or feel like a setback. Just remember that rejection for intestinal patients is very common due to the high amounts of immune tissue in the organ. The good thing is that your team will be vigilant in monitoring you and will have medicine, like Thmyoglobulin, to help treat you when rejection episodes do occur.

PROPHYLACTIC MEDICATIONS (MEDICATIONS TAKEN TO PREVENT INFECTION)

Valganciclovir (Valcyte)

Antiviral used to treat or prevent cytomegalovirus (CMV). It comes in tablet form and should be taken with food or on a full stomach for full absorption.

Common Side Effects

- Headache
- Diarrhea
- Nausea
- Vomiting
- Upset stomach
- Low white blood cells
- Low platelets

Important Tips and Special Instructions:

- Store in room temperature, away from excess heat, moisture, and direct sunlight.
- Missed Dose: If missed take as soon as possible; if close to the next dose do not take a double dose.

Acyclovir (Zovirax)

Prophylactically used as an antiviral to prevent and treat infections caused by viruses, particularly herpes virus; also used to treat chicken pox and shingles. It comes in the form of tablets, capsules, or liquid suspension.

Common Side Effects

- Tiredness
- Lightheadedness
- Headache
- Nausea or vomiting
- Abdominal pain
- Skin reactions
- Kidney problems

Important Tips and Special Instructions:

- Most effective when taken as soon as possible after you notice symptoms of herpes infection (i.e. pain, burning, blisters).
- Does not prevent the spread of herpes virus.

PROPHYLACTIC MEDICATIONS (MEDICATIONS TAKEN TO PREVENT INFECTION)

Sulfamethoxazole/ Trimethoprim (Bactrim)

Prophylactic antibiotic used to prevent a type of pneumonia caused by pneumocystis jiroveci and comes in the form of a tablet.

Common Side Effects

- Anemia
- Sensitivity to sunlight
- Dizziness
- Diarrhea
- Headache
- Loss of appetite
- Nausea, vomiting
- Skin rash

Important Tips and Special Instructions:

- Take exactly as prescribed with a full glass of water.
- Drink enough fluids throughout the day.
- Missed Dose: If missed take as soon as possible; if close to the next dose do not take a double dose.

Pentamidine (NebuPent)

Antibiotic used to prevent a type of pneumonia caused by Pneumocystis jiroveci used for patients with a sulfa allergy or who cannot tolerate oral Bactrim. It is inhaled into the body via a breathing treatment.

Common Side Effects

- **Dizziness**
- **Metallic taste**
- **Fatigue**
- **Loss of appetite**
- **Diarrhea**
- **Cough**
- **Upset stomach**
- **Congestion**

PROPHYLACTIC MEDICATIONS (MEDICATIONS TAKEN TO PREVENT INFECTION)

Nystatin

Prevent fungal infections of mouth and throat, including thrush (i.e. candidiasis). It comes in the form of liquid, dry powder, or lozenges.

Common Side Effects

- Abdominal pain or cramping
- Diarrhea
- Nausea or vomiting
- Abnormal taste

Important Tips and Special Instructions:

- Swish liquid in your mouth for at least five minutes before gargling and swallowing.
- For lozenges, allow lozenge to dissolve in your mouth for 15-30 minutes, do not chew.
- Do not eat or drink anything for at least 30 minutes after taking this medication.
- Brush your teeth 30-60 minutes after taking the medication to prevent tooth decay.

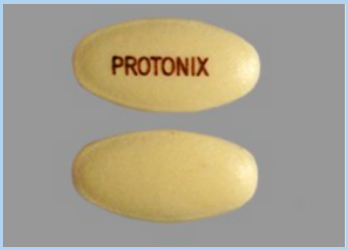
OTHER COMMON MEDICATIONS POST- TRANSPLANT

Pantoprazole (Protonix)

This is a common medication that you may have been on before transplant. The function of this medication is to treat acid reflux by reducing the amount of acid the stomach produces, and is known as a proton-pump inhibitor. It usually comes in tablet form.

Common Side Effects

- Headache
- Dizziness
- Abdominal pain
- Nausea and/or vomiting



Metoclopramide (Reglan)

The purpose of this medication is to speed up the emptying of the stomach and the movement of the upper portion of the small intestines. Your transplant team may prescribe this to you if you are having trouble with slow motility or nausea after your transplant. It usually comes in the form of a tablet.

Common Side Effects

- Tiredness
- Trouble sleeping
- Agitation
- Headache
- Diarrhea
- Dizziness

OTHER COMMON MEDICATIONS POST- TRANSPLANT

Anti-Coagulants (Blood Thinners)

Both of these medications function to prevent and treat blood clots by lowering the activity of clotting proteins in your blood. It comes in the form of a tablet. This medication requires close monitoring and usually will require you to have your blood drawn regularly. You also need to be aware that you can bleed easily on this medication, so you should be careful if you become injured.

Warfarin (Coumadin)

Common Side Effects

- Nausea, vomiting, stomach pain
- Bloating, gas
- Altered sense of taste
- Easy bruising, purple or red pinpoint spots on the skin

Important Tips and Special Instructions:

- Interacts with many drugs, should check to see if any of your medications will interact

Enoxaparin (Lovenox)

Common Side Effects

- Pain, bruising, swelling at the injection site
- Nausea
- Diarrhea
- Swelling in hands or feet
- Fever

Important Tips and Special Instructions:

- Use extra caution with sharp objects to avoid getting cut, bruised or injured.
- Avoid contact sports.

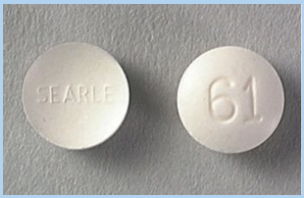
OTHER COMMON MEDICATIONS POST- TRANSPLANT

Loperamide (Lomotil)

In the form of tablets. Your transplant team might suggest this medication if you are having high output from your ostomy and frequent bouts of dehydration.

Common Side Effects

- Dizziness
- Tiredness
- Constipation



Helpful Resources

RxAssist: Website that is a comprehensive directory of patient medication assistance programs. Search for a medication and the directory will list the available assistance programs for the particular medication.

Rx Outreach: Access to affordable meds. Non-profit pharmacy.

Transplant Hero: Phone app that helps you track your immunosuppression medications.

POST-TRANSPLANT RESPONSIBILITIES: MEDICATION ADMINISTRATION

After transplant it is of **paramount importance** that you take medications as directed and comply with all instructions and guidelines. Here are important tips when it comes to medications:

- Learn the name of each new medication and why it's being used.
- Learn how the medications should be taken (when, how much to give, and how to give).
- Practice giving the medications while still in the hospital. Always check the medications with the nurses before you take them while in the hospital.
- Learn a good routine while in the hospital, because you will be expected to take all medications as prescribed once you go home.
- Your home medication schedule may be different than the hospital schedule. It will be crucial to use the printed medication schedule the transplant team provides you upon discharge.
- Medication doses may change frequently. Use your printed medication schedule, not the prescription bottles to determine how much medication to give.
- Carry your medication list with you at all times.
- Always have extra anti-rejection medication with you just in case you get stuck somewhere or drop a pill on accident.

Please note: Always refer to your transplant team or pharmacist for specific questions regarding your medication regimen.

POST-TRANSPLANT RESPONSIBILITIES: APPOINTMENTS AND TESTS

It is critical to **keep all follow-up appointments** as scheduled with the transplant team. These appointments are vital in keeping your new intestine functioning properly and allow you to ask questions regarding the recovery process.

- At first, you will likely be seen twice weekly for follow-up appointments and the frequency will decrease as you become more stable.

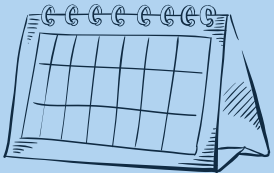
- At the appointment, the following will be **reviewed:**
  - Symptoms, both new and ongoing.
  - Input and output records.
  - Nutritional and hydration status.

- Lab work will be done twice weekly immediately after discharge, and then the frequency will decrease as you become more stable
  - **Do not take anti-rejection medications the morning of bloodwork until after** the blood has been drawn, this allows for the trough (bottom) level of the medication to be monitored.

- Once discharged, you will have an ileoscopy (biopsy/ or scope) of the new intestine every 7-10 days until you are more stable and are not showing signs of rejection. This varies per center. Please speak with your team for the exact plan of care for you.

- You may have appointments with other departments, such as infectious disease, to monitor your health status.
  - These are just as important to keep as the appointments with the transplant team.

Please note: The number of clinic visits, lab work, etc. on this page are just general frequencies. Every transplant center and patient will vary depending on a variety of parameters.



POST-TRANSPLANT RESPONSIBILITIES: VITAL SIGNS

Body Temperature

- Keep a temperature record.
- Always check your temperature when you wake up first thing in the morning.
- If you ever feel clammy or have chills/ feel like you have a fever, then check your temperature.
- In the event you do have a temperature >100.4o F call your transplant coordinator (actual temperatures may vary per transplant center guidelines).

Blood Pressure and Heart Rate

- Keep a blood pressure (BP) and heart rate (HR) record.
- If you don't know how to take a BP and HR, someone can teach you.
- Always check your blood pressure first thing in the morning when you wake up and/or as indicated by your transplant team.
- You may be asked to check your blood pressure prior to taking blood pressure medications in order to determine if you are within your parameters for taking your medications.
- For your heart rate, if you are using an automatic BP cuff, it will automatically provide your heartrate. If you are manually taking a blood pressure, then you will need to manually take your pulse.

Weight

- You should always take your weight at the same time of day with the same type of clothing.
- It is best to weigh yourself first thing in the morning right when you have woken up.
- Record your daily weights and notify your transplant team with any major changes.

POST-TRANSPLANT RESPONSIBILITIES: WHEN TO CALL YOUR TRANSPLANT TEAM

It is very important to notify your transplant team if you are feeling unwell as this may be a sign of rejection, infection, or another illness that may lead to significant harm. The list below contains recommendations of when to call your transplant team, but is not an all-inclusive list, and you should always refer to your respective transplant center when seeking any particular advice.

- Changes in vital signs (blood pressure or heart rate significantly increases or decreases).
- Fever >100.4o. F (or extremely low temperature <96o F)
- Difficulty breathing or shortness of breath.
- Cough, congestion, or runny nose.
- Increased abdominal pain.
- Extreme nausea and/or vomiting.
- Blood in stool, urine, or vomit.
- Decrease in urine output.
- Chills or sweats.
- Sore throat.
- Significant fatigue out of the ordinary.

If you are experiencing a life-threatening emergency, proceed to the nearest emergency room or dial 911.

CONTACTING YOUR DONOR FAMILY

Sometimes donor families and recipients decide to contact one another. The decision to contact your donor family is entirely your own. Some people find comfort in correspondence, while others prefer not to make this choice. Either way you choose, the correspondence must be coordinated through the transplant center and the organ procurement organization (OPO). Each transplant center may have different procedures for contacting donor families, so you should talk to your transplant coordinator or OPO for specific recommendations and requirements. Each transplant center and OPO have policies in place to protect the privacy of both parties. Correspondence remains private, unless both parties decide to meet.

In general, when you are writing your letter things you want to avoid include:

- Any specific information about yourself or your family (i.e. age, where you live).
- The name of your surgeon or transplant center.
- Religious terminology.

Things that are okay to include:

- How grateful you are for their loved one's donation.
- Awareness of the donor family's loss.
- Something about yourself and your family (hobbies, interests).
- The difference the transplant made in your life (how you feel, what you are able to do).
- What you have been able to do after transplant (any life events like marriage, graduation, travel, the birth of children or grandchildren).

Confidentiality

There is no law that prevents a recipient and donor family from meeting, however, all OPO's will have policies in place to protect the privacy of both parties. This is important because one party may feel uncomfortable with the situation and the OPO's goal is to make the exchange of communication as smooth as possible.

CONTACTING YOUR DONOR FAMILY

Mailing your Letter- General Guidelines

1. Place your card in an unsealed envelope.
2. Include a separate piece of paper with your full name and the date of your transplant.
3. Place these items in another envelope and mail them to your transplant center.

What happens once the transplant center receives your letter?

1. The transplant center will forward your letter to your OPO.
2. A coordinator from the OPO will review it to ensure confidentiality.
3. The coordinator will then contact the donor family to ask if they wish to accept correspondence from recipients.
4. If the donor family does not wish to communicate, the OPO will inform your transplant center accordingly.
5. If the donor family does wish to communicate, the OPO will forward your letter to them.

Note: It may take several weeks for your letter to actually reach the donor family.

Hearing from the Donor's Family

You may or may not hear from the donor's family if you choose to write a letter. It is completely up to the donor's family whether or not they choose to accept the correspondence and it is their decision if they choose to respond to the letter. If the family does choose do respond, the family will send their letter to the OPO, and the OPO will forward the message to you.

If you wish to learn more information on this topic please visit the Transplant Living Page **here.**

LIFE AFTER TRANSPLANT

After an intestinal transplant, many things in your life and lifestyle will change because of the new medications you are on to help keep your new organ (s) healthy. Anti-rejection medications, or immunosuppressants, suppress your immune system, making your body more susceptible to infections. Because of this, there are many precautions you must take after transplant to make sure you stay healthy, infection, and rejection free!

Preventing Infection

- Do not eat or drink after other people (i.e. do not share food or drinks).
- Do not share razors, toothbrushes, or eating and drinking utensils.
- Wash hands frequently and with soap and water- if soap and water is not available, use hand sanitizer.
- Keep hands away from eyes, nose, and mouth. Keep sick visitors away from your home.
- Avoid large crowds, particularly in the first six months after transplant, when you are particularly immunosuppressed.
- Avoid drinking water that comes from a well.
- If anyone at home becomes sick, try to stay away from them. If you are close to a sick family member, make sure they cover their mouth if they sneeze or cough and frequently wash their hands.
  - If you share a bathroom, use separate hand towels.
- Do not share a toothbrush.
- Wipe down surfaces with disinfectant wipes often, including:
  - Tables, counters in the kitchen/bathroom, etc.
  - RemotesLight switches
  - Door handles
  - Sinks
  - Toilets, bathroom surfaces
  - Any other surfaces that you may touch frequently (i.e., cellphones, computers)
- Keep immunizations up-to-date.

Handwashing 101

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

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 vigourously.

Source:
World Health Organization

LIFE AFTER TRANSPLANT

Immunizations

What are they? An immunization or vaccine is a shot that is given to prevent a future illness.

After transplant, you are at **higher risk of infection**. This means, you should:

- Stay up-to-date on all recommended immunizations.
- Receive the flu shot annually.
- Wait at least 3-6 months post-transplant to receive any vaccinations or per your transplant teams recommendations.
- **Do not receive live virus vaccinations** (see **our website** for more details).
- Keep a record of all immunizations.

To **protect you** from infection, all others in your household should:

- Receive the flu shot annually.
- Stay up-to-date on all vaccinations.
- Ask your transplant team about measures to take if a family member has received a live virus vaccine.

Pets

Pets can be a great stress reliever and bring happiness to you after transplant; however, it is also important to realize that your pets can also carry many germs that can make you sick. You must follow certain precautions after your transplant with your pets to ensure that you keep yourself and your pet safe, healthy, and infection-free. Read more **here.**

Rinse all fruit and vegetables under running water.

Refrigerate or freeze perishable foods within **2 hours** of buying, peeling, cutting, or cooking.

Throw away refrigerated leftovers after **3 days** or earlier if they appear or smell spoiled.

Drink **treated or filtered** water. Annually test water for any contaminants. Do not drink well water. **Avoid using ice cubes**, especially at restaurants, as ice cube makers often harbor mold.

Use a food thermometer for cooking the internal temperature of meat to at least **165 degrees** F.

The recommendation is to eat **hot food hot** and **cold food cold.** Do not consume food sitting out for long periods, such as buffets or supermarket delis.

Avoid foods with **raw** or undercooked **eggs,** such as and Caesar salad, Hollandaise sauce.

Separate cooked and raw foods. Use cleaned or **separate cutting boards** and knives for prep.

LIFE AFTER TRANSPLANT

There are many more topics on **Life After Transplant.**
Here is a list of topics that you can find on **our website:**

Preventing Infection	Monitoring Your Cholesterol Levels
Things to Avoid	Post-Transplant Screening
Bug Safety	Preventing Food Borne Illness
Exercise and Activity	Pet Safety
Immunizations	Nutrition Post-Transplant
Post-Transplant	Post-Transplant Eating Tips
Medical Identification	Returning to Work
Dental Care	Pregnancy After Transplant
Eye Care	Tattoos and Piercings
Skin Care	Post-Transplant
Sun Safety	Dealing with Your Emotions
Post-Transplant Diabetes	General Medication Tips
Joint Replacement	General Traveling Tips
Dialysis	Travel Vaccinations

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Communication is Key

As a patient going through an intestinal transplant it is important to educate yourself as much as possible. Having a general understanding of intestinal transplant will allow you to advocate for yourself and communicate your needs with your transplant team and caregivers to ensure you receive the best care possible.

More Info?

info@transplantunwrapped.org

www.transplantunwrapped.org

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References for this Handbook can be found **here.**